S. HRG. 119–301

AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS

HEARING

BEFORE THE

SPECIAL COMMITTEE ON AGING

UNITED STATES SENATE

ONE HUNDRED NINETEENTH CONGRESS

FIRST SESSION

WASHINGTON, DC

DECEMBER 3, 2025

Serial No. 119–20

Printed for the use of the Special Committee on Aging



Available via the World Wide Web: http://www.govinfo.gov

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U.S. GOVERNMENT PUBLISHING OFFICE

62–922 PDF WASHINGTON : 2026

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AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS

Wednesday, December 3, 2025

U.S. SENATE
SPECIAL COMMITTEE ON AGING
Washington, DC.

The Committee met, pursuant to notice, at 3:10 p.m., Room 216, Hart Senate Office Building, Hon. Rick Scott, Chairman of the Committee, presiding.

Present: Senator Scott, Moody, Gillibrand, Warnock, Kim, and Alsobrooks.

OPENING STATEMENT OF SENATOR RICK SCOTT, CHAIRMAN

The CHAIRMAN. The U.S. Senate Special Committee on Aging will now come to order. Today's hearing is meant to bring attention to an incredibly important issue for so many of America's seniors, especially as we move into the holiday season. We are here to focus on how to best serve older Americans who want to spend their senior years in the comfort of their own homes.

While there are so many positives about aging in place that we'll highlight today, we're also here to shine a light on the often-unreported crisis of isolation and loneliness. We should be doing everything possible to support seniors who strive to age in place, and today we'll focus on how Congress can reauthorize the Older Americans Act, known as the OAA to continue many critical programs that support seniors with this goal.

Last week, we all celebrated Thanksgiving, and later this month families across America will be celebrating Hanukkah and Christmas. For many of us, that means spending time with family and loved ones. My case, I got to help my five-year-old granddaughter win UNO. She loved giving away plus fours to people.

I learned two-thirds of how to do a Rubik's Cube because that's what my twelve-year grandson does.

Senator GILLIBRAND. Wow. Impressed.

The CHAIRMAN. He told me that the last part was the hardest. While these moments are a time to cherish time with loved ones, they can also be a difficult reminder of loss for older Americans who no longer have the ability to spend the holidays with their friends, spouse or even their children.

We all know the importance of taking care of our seniors. For many older Americans who choose to age in place, our goal should

always be to help them have the best possible care and support. They should always have the opportunity to remain in the homes and neighborhoods they love.

That is why community, strong families, faith-based organizations, volunteers, OAA programs are so important to our aging population, especially during this time of year. In my home State of Florida, which is quite a bit warmer than it is here, there are many seniors who cannot travel during the holiday season.

Thankfully, many communities have the resources to give our seniors the care and attention they deserve. Combating the feeling of isolation and loneliness for our aging community has endless benefits from better mental and physical health to stronger multigenerational relationships with families and communities, supporting healthier, more resilient communities.

We can all agree that community matters. Strong families, faith-based organizations, volunteers, and the program supported by the OAA create the foundation that allows older Americans who choose to age in place to remain in the homes and neighborhoods they love. That's why supporting the successful programs made possible by the OAA ensuring how faith-based groups, nonprofits, and service organizations strengthen families is so important to the work of this Committee.

During the holidays, when both loneliness and the demand for caregiving arise, these supports become even more critical. Aging place is good for families, communities, and taxpayers. Strengthening these programs is a bipartisan commitment to dignity, independence, and the American way of life.

For 60 years, the OAA has helped innumerable seniors by promoting social connection and life affirming support programs. Over 10 million older Americans a year are helped by programs covered by the OAA. The OAA continues to serve as the backbone of many assistance programs that help ensure older Americans can age in place with dignity.

I'm proud to work with Ranking Member Gillibrand as well as Health, Education, Labor and Pension Committee Chairman Cassidy and Ranking Member Sanders to fight for the reauthorization of this important piece of legislation, which is a critical tool in our arsenal to support seniors. I'm also working with fellow committee member Senator Warnock on legislation to address senior home loneliness through Older American Act funding. By Senior Act expands the scope of grants to include services that address the loneliness epidemic facing seniors.

I'm working to pass bipartisan legislation to create a non-refundable tax credit aimed at adults who provide certain care for their parents or older relatives in multi-generational households. My hope is that with this hearing, we can examine how strong community networks help older adult age in place, especially during the holiday season when isolation caregiver stress and multigenerational pressures peak.

Now, I can recognize Ranking Member Gillibrand from the cold, cold state today of—it's snowy there?

Senator GILLIBRAND. It's cold.

The CHAIRMAN. It's snowy, too.

Senator GILLIBRAND. Yes, I bet it is.

The CHAIRMAN. For her opening statement.

OPENING STATEMENT OF SENATOR KIRSTEN E. GILLIBRAND, RANKING MEMBER

Senator GILLIBRAND. Thank you, Mr. Chairman. Thank you for calling today's hearing. Thank you to our witnesses. Thank you for being here. The holidays are when communities come together. Whether you celebrate with family or friends or loved ones, sharing this heartfelt season with the people you love makes all the difference in the world.

However, building and participating in one's community is a year-round endeavor and one that can pose unique challenges for older adults and people with disabilities. The most important mechanism that enables this kind of participation is home and community-based services, or HCBS. HCBS is almost exclusively available through Medicaid, and the availability of services is tied to federal funding.

Our witnesses today will discuss the importance of these programs and how they allow older adults and people with disabilities to live in their communities, which is their overwhelming preference to institutional care. With this in mind, I am pleased to enter more than 600 statements from people, families, and organizations about the impact of HCBS for older adults and people with disabilities into the congressional record.

Our witnesses will also discuss the importance of including these populations in decision-making processes that directly impact them. This is why today I'm reintroducing my Strategic Plan for Aging Act. This bill will help states create multi-sectoral plans for aging, including those who are aging with a disability, while ensuring the needs, preferences, and views of the people directly impacted are prioritized in the development and implementation of a plan.

I'm especially proud to introduce this bill today on the International Day of Persons with Disabilities. People with disabilities should always be included in decisions about their lives, health, and well-being. I look forward to the discussion about my Strategic Plan for Aging Act that will help create inclusive and effective state plans. Thank you, Mr. Chairman.

The CHAIRMAN. Thank you, Ranking Member. I'd like to welcome our witnesses, all of whom work to ensure aging Americans and seniors with disabilities age in place, especially during the holidays, to ensure they remain safe and engaged.

First, I'd like to introduce John Offerdahl. John, who proudly hails from the great State of Florida is the president of Offerdahl's Hand-off Foundation. In 2012, Mr. Offerdahl established the Offerdahl Hand-off Foundation. His organization's mission is to ″Feed the needs of those in crisis.″

In partnership with business, government, civic, and faith-based organizations. When the Covid pandemic hit our Nation, Mr. Offerdahl saw a need and stepped up in a big way to serve seniors in Broward County. Mr. Offerdahl thanks for being here. Please begin your testimony.

**STATEMENT OF JOHN OFFERDAHL,
PRESIDENT, OFFERDAHL'S HAND-OFF
FOUNDATION OAKLAND PARK, FLORIDA**

Mr. OFFERDAHL. Chairman Scott, Ranking Member Gillibrand, and members of the Committee, it is an honor to speak with you today about an issue affecting millions of older Americans, ensuring that seniors can age in place with dignity, safety, independence, and meaningful human connection.

As mentioned, my name is John Offerdahl, and I'm the Hand-Off Meals for Seniors president. We are an older American Act, home delivered meals service provider in Broward County. I've been a resident of Broward County since 1986, when Coach Shula drafted me as a Miami Dolphin. I went on to spend my entire 8-year NFL career in South Florida.

Since then, my wife and I have owned restaurants and been involved in charitable work, including our own Offerdahl's Hand-Off Foundation. How does an NFL linebacker become a provider of senior meals? Hand-Off Meals was born during COVID when Miami Dolphin owners, Stephen Ross, reached out to Dolphin alumni, who are also restaurateurs to produce and deliver emergency meals in the neighborhoods surrounding Hard Rock Stadium.

With additional support from generous partners, we delivered more than one million meals across Broward County, many for homebound seniors. In the years that followed, emergency COVID funding through the Area Agency on Aging of Broward County and the Florida Department of Elder Affairs, allowed us to continue this work. By 2023, our team had delivered hundreds of thousands of fresh restaurant quality meals to vulnerable seniors and families who needed them most.

The success of these efforts led the Broward AAA, under the leadership of CEO Charlotte Mather Taylor, to rethink a new model for its home delivered meals program. For the first time, rather than awarding one contract to the lowest cost frozen meal provider, our program, Hand-Off meals was one of four contracts awarded after a competitive bidding process.

Today, Hand-Off Meals for Seniors is the leading meal provider in Broward County, delivering more than 4,500 fresh restaurant quality home delivered meals every week. Now, this is why I'm here today. I want to emphasize why the improvements in this model matter. Broward County reflects the future of our Nation. Florida has one of the highest concentrations of seniors in America and Broward's population of adults over 85 is projected to increase by 169 percent over the next 25 years.

The choice between aging in the home or entering institutional care often hinges on improvements unleashed by competition. Here are four improvements we have driven so far in Broward County.

One, competition among providers promotes better quality, better services, and outcomes. Providers like us are food centric, not large institutional frozen meal brokers. Most meals we deliver include fresh salads, sandwiches, fruits, vegetables versus institutional frozen meals. While fresh ingredients and real time production are more expensive, local production and scattered restaurants across Broward County creates decentralized pickup points that make the system efficient and sustainable.

Two, competition among providers inspires innovation and efficiencies that lower costs. Providers can leverage a restaurant's purchasing power, fixed cost, and community commitment to provide high quality meals at a sustainable rate. Discounting profits and service of the community-oriented mission.

Three, competition among providers invigorates public private partnerships. Funding partnerships have expanded, supported by organizations like the Jim Moran Foundation, Community Foundation of Broward, Miami Dolphins Foundations, public charities, Walgreens, to help cover the gap between public funds and the elevated cost of quality restaurant fresh meals.

Fourth, competition among providers give seniors more choice. Seniors retain personal agency over their choice of choice of meals, delivery, relationships, and aging in place decisions. In conclusion, this is the kind of improvement we all hope to see from our government programs. Better outcomes, lower costs, invigorated partnerships, and more choice.

Competition among home delivered meal providers is good for the body and soul of our aging and place seniors. At every level, this work is a public private partnership, and the Older American Act is the backbone of the team. As Coach Shula taught us, in life as in football, it takes a team.

Chairman Scott, Ranking Member Gillibrand and members of the Committee, the Hand-Off Meals for Seniors program demonstrates what becomes possible when fresh high-quality nutrition is paired with consistent human connection and allowed to compete for the hunger and heart of our seniors.

I invite every member of this Committee to visit us in Broward County, meet our volunteers, talk with our seniors, and join my wife Lynn, and me on one of our weekly meal deliveries. I truly believe you'll be inspired. Thank you.

The CHAIRMAN. Thank you, Mr. Offerdahl. Now, we're going to hear from Jason Resendez. He's the CEO of National Alliance of Caregiving. In this role, he spearheads research policy and innovation initiatives to build wealth, health, and equity for Americans, 53 million family givers. Please begin your testimony.

STATEMENT OF JASON RESENDEZ, CEO NATIONAL ALLIANCE FOR CAREGIVING WASHINGTON, DC

Mr. RESENDEZ. Good afternoon, Chairman Scott, Ranking Member Gillibrand, and members of the Committee. Thank you for the opportunity to testify about the role that family caregivers play in enabling older adults to age in place in their communities. My name is Jason Resendez and I'm the president and CEO of the National Alliance for Caregiving.

For nearly 30 years, we've documented the experiences of America's family caregivers and right now we are living through a profound demographic shift. Every day, 10,000 Americans turn 65. This is a tremendous achievement but it presents challenges that largely fall on the shoulders of our Nation's family caregivers who make up the backbone of our Nation's long-term care system.

These are our neighbors, our coworkers, our friends, our family members, many of you, and they've never been under more pressure. According to our landmark caregiving in the U.S. 2025 re-

search with AARP,63 million Americans, nearly one in four now provide care for a loved one who is aging seriously ill or is living with a disability. That's a nearly 50 percent increase since 2015.

This surge mirrors a critical reality. 70 percent of older Americans need long-term services and supports during their lifetime. Caregiving has become more prevalent, more intensive, and more isolating. One in three family caregivers are in the sandwich generation, providing care for children and adults simultaneously. On average, they spend 27 hours per week providing care and nearly one in four provide 40 or more hours weekly, the equivalent of a full-time job.

These caregivers provide complex support, more than half administer medications, manage special diets, and change feeding tubes and family caregivers enable something Americans overwhelmingly desire, the ability to age and receive care at home. This matters for two fundamental reasons.

First, dignity at home. When people age in place, they maintain control over their care and their lives. Second, simple economics. We can support more than two people at home for the cost of one person in a nursing facility but despite their heroism and their economic value, caregivers face a growing crisis. Nearly two thirds experience high emotional stress, 45 percent report physical strain.

Nearly half have experienced negative financial impacts because of their care responsibilities and these impacts are not evenly distributed. Caregivers of color, rural, lower income and youth caregivers face the greatest hardships. For example, 28 percent of lower income caregivers cannot afford basic expenses like food compared to eight percent of higher income caregivers. Congress recognized this reality 25 years ago when it created the National Family Caregivers Support Program through the Older Americans Act.

The program provides what caregivers need most. Respite care, counseling, training, and referral services, acknowledging the vital role that family caregivers play in supporting older adults, yet we must go further. Under current Medicaid rules, access to institutional care is an entitlement. While staying at home requires a waiver, we need to flip this paradigm. The right thing should be to remain in your home with institutional care as an option, the backup not the default.

Consider this, as of 2020 just 12 states spent at least half their Medicaid long-term care dollars on home and community-based services for older adults and adults with physical disabilities. That means 39 states still spend the majority on institutional care. In these places, older Americans and people with disabilities who need long-term support often don't have real options to stay at home.

The older Americans Act demonstrates what's possible when we invest in keeping people at home through home delivered meals, transportation, and caregiver support. We must reauthorize and fully fund Older Americans Act programs to strengthen the aging network that connects family caregivers with the support they need, and we must pair these investments with smart economic policies that recognize the true value family caregivers contribute to our economy. We already have a strong legislative foundation to build on.

The multi-generational home caregiver tax credit led by Senator Scott and Welch acknowledges the essential work that family members provide within intergenerational households and the Family Act introduced by Ranking Member Gillibrand would establish a national paid family and medical leave program, giving workers the security they need to care for loved ones without sacrificing their financial stability.

Along with the Older Americans Act, these bills represent concrete steps toward building a care infrastructure that supports families across generations. After nearly three decades of listening to family caregivers tell their stories, one truth is undeniable. These are ordinary Americans doing extraordinary work that benefits all of us.

When we invest in family caregivers, we strengthen families and build communities where no one faces their hardest moments alone. That's what makes community living possible.

Thank you for this opportunity to testify today and I'm happy to answer your questions.

The CHAIRMAN. Thank you, Mr. Resendez. Now, I'd like to recognize Ranking Member Gillibrand to introduce our next witnesses.

Senator GILLIBRAND. Thank you, Chairman Scott. I'd like to introduce our next witness, Alison Barkoff. Professor Barkoff is the director of the Hirsh Health Law and Policy Program at George Washington University. Professor Barkoff led the administration for Community living ACL in the U.S. Department of Health and Human Services from 2021 to October 2024, serving as ACL administrator and assistant secretary for Aging.

Previously, she served as special counsel for Olmstead Enforcement in the Civil Rights Division of the U.S. Department of Justice. Professor Barkoff, you may begin your testimony.

STATEMENT OF ALISON BARKOFF, JD, HIRSH HEALTH LAW & POLICY ASSOCIATE PROFESSOR AND DIRECTOR OF THE HIRSH HEALTH LAW & POLICY PROGRAM, GEORGE WASHINGTON UNIVERSITY, FORMER ACTING ASSISTANT SECRETARY FOR AGING AND ADMINISTRATOR, ADMINISTRATION FOR COMMUNITY LIVING, DEPARTMENT OF HEALTH AND HUMAN SERVICES, WASHINGTON, DC

Dr. BARKOFF. Good afternoon, Chairman Scott, Ranking Member Gillibrand, and members of the Committee. Thank you for inviting me to participate in today's hearing on Community Living and Aging in place. My name is Alison Barkoff, and I have more than 25 years' experience in disability, aging, and community living policy. The vast majority of older adults and people with disabilities want to live in their own homes and communities instead of in nursing homes or other institutions.

It allows them to be with family and friends, participate in community activities, work or volunteer, and age in place. Community living is cost effective and leads to better outcomes, and federal laws and Supreme Court precedent establish the right to receive services in the community instead of institutions.

The demand for community living is growing exponentially with more than 10,000 people turning 65 every day and disabled people living longer, often with aging caregivers. There has been bipar-

tisan support for policies and programs that make community living possible.

Many older adults and disabled people require assistance to live in their own communities and age in place. I'm going to briefly discuss the major programs that provide these supports. First and most importantly, Medicaid funds, home, and community-based services, or HCBS. HCBS includes home care, senior day programs, disability employment supports, respite care and more.

Neither private health insurance nor Medicare cover these services and most people cannot afford to pay out of pocket. Medicaid law requires states to provide institutional care but HCBS are optional. States can cap enrollment in HCBS programs leading to more than 600,000 people on waiting lists. The aging and disability communities have urged Congress to address this institutional bias and put HCBS on equal footing with institutional care.

Despite their optional nature, states have been steadily expanding their HCBS programs. These efforts must continue and accelerate to meet growing demand and need, yet reductions in Federal Medicaid spending to states could put optional services like HCBS at risk for cuts. Older Americans Act programs also help people age in place. They support one in five Americans over 60 with personal care, transportation, family caregiver supports home delivered meals and more.

OAA programs complement Medicaid. They can serve people who aren't yet eligible or on HCBS' waiting list. Annually, they save hundreds of millions of dollars to Medicare and Medicaid by preventing unnecessary emergency room hospital and nursing home admissions. Many OAA programs already have waiting lists and demand is quickly growing.

Reauthorization of the OAA and increased investment in its programs is critical to helping older adults age in place. Other programs provide community living supports for disabled people of all ages. This includes independent living services and Developmental Disabilities Act programs that help people access community services.

Demand for these programs similarly, outpaces need and continued investment in them is essential. We often forget about the ″H″ in home and community-based services, but people cannot live in the community without a home that is both affordable and accessible. Less than five percent of housing stock is accessible, and many older adults and disabled people spend more than a third of their income on housing, often foregoing medical care or food.

Many are at risk of homelessness and the fact is, older adults are the quickest growing homeless population. Federal housing programs are also critical to community living. Finally, the Administration for Community Living funds and overseas community living programs and leads cross agency initiatives to address barriers like housing and workforce shortages. Importantly, ACL coordinates to ensure that older adults and disabled people are considered across federal policies.

ACL has been impacted by HHS' reduction in force, losing almost half of its staff this calendar year. Congress should ensure that ACL is sufficiently resourced to fulfill its statutory mandates, support its programs, and coordinate policy across the Federal Govern-

ment. Thank you for this opportunity to testify about the importance of community living and what it takes to make that a reality for the millions of older adults and people with disabilities in this country. Thank you.

Senator GILLIBRAND. I want to move to our next witness, Emily Ladau. Ms. Ladau is a disability rights activist, author, speaker, and digital communications consultant. In her current role, she provides consultation and editorial services and manages online presence and communications strategies for multiple disability related organizations and initiatives.

In addition to her written work being published in outlets, including New York Times, SELF, Salon, Vice, HuffPost, Ms. Ladau is author of Demystifying Disability: What to Know, What to Say, and How to Be an Ally. Ms. Ladau, you may now begin your testimony.

STATEMENT OF EMILY LADAU, DISABILITY RIGHTS ADVOCATE AND AUTHOR OF DEMYSTIFYING DISABILITY, WEST NEW YORK, NEW JERSEY

Ms. LADAU. Chairman Scott, Ranking Member Gillibrand, and distinguished committee members, I am honored to testify on this auspicious day as December 3rd is the International Day of People with Disabilities. I am a proud disability advocate and my mission is to harness the power of storytelling as a tool to expand accessibility and inclusion for all.

As a 34-year-old, my story may seem out of place at a hearing about aging in place but the disability perspective is especially pertinent to today's focus on the impact of community. I want to emphasize that more than one in four adults in the United States have a disability and of this group, 43.9 percent are adults aged 65 or older. For those who are not yet disabled, there is a significant likelihood of aging into disability.

Neither a person's age nor disability status should ever be a barrier to being among loved ones in our homes and communities. When I was a teenager, my parents and I took a trip to Florida to visit my grandparents for a holiday celebration. At the time, my grandpa was in the midst of an extended hospital stay but his doctor permitted him to come home for a few hours to join us for a holiday meal.

As my family was cooking, I sat with my grandpa while he opened the day's mail. He began to weep over the simple act of being able to do a task in his own home. It is the only time I ever saw him cry, and as I look back on this moment, I realized just how strongly it underscores the immense importance of being home and not just for the holidays.

I was born with my physical disability, so I know well the essential nature of supports and services that empower me to thrive at home and in my community and how fortunate I am to have had access to them throughout my life. When my mom, who has the same disability as me, was born in 1961, a family member suggested that my grandparents place her in an institution.

Thirty years later when I was born, no one made this suggestion to my parents. Instead, following my stay in the neonatal intensive care unit, a public health nurse connected my mom with resources

to ensure that I would receive the care I needed. Because of this, I was able to have regular physical, occupational and speech therapy starting at just a few months old.

By the time I began kindergarten, I was approved for ongoing Home and Community-Based Services, or HCBS, thanks to the New York State Care at Home Medicaid Waiver. Medicaid provided me access not only to vital therapeutic services, but also to home modifications that enabled me to function as independently as possible in my family's home. Medicaid also assisted in the acquisition of durable medical equipment such as my power wheelchair.

As you can see by the fact that I'm here today, my wheelchair gives me freedom to be out and about in the community. Unfortunately, the Medicaid asset limit, which has been a mere $2,000 for over 35 years, became prohibitive to my future career and relationship goals. In my early thirties, I found myself at an inflection point. I wanted to forge ahead in my career and build a life with my partner, but I was trapped in an inflexible system that imposes caps and penalties on people in exchange for access to life saving services.

With family support, which most people cannot afford, I took a risk and decided not to reapply for Medicaid. That said, what I am sharing is not a success story about transitioning off Medicaid as this choice has meant foregoing needed care, such as in-home physical therapy multiple times per week, which I can only access through the Medicaid program.

The story here is that HCBS provided by Medicaid was what set me up for success. This past October, I married the love of my life and my husband and I are now seeking a community to call home near our families in New Jersey. We are searching for somewhere accessible for my physical needs at this stage of our lives as well as for our future needs so we can safely age in place. This search has proven arduous in a housing market where accessible homes are nearly non-existent.

Our experiences are a stark reminder that the stakes of today's hearing are much higher than heartwarming tales of being home for the holidays. Without access to HCBS and without efforts to prioritize housing in communities that work for everyone, people with disabilities and older adults will all too easily be pushed out of our homes and communities and into institutionalized settings, denied opportunities for everything from education and employment to recreation and socialization.

We won't be the only ones missing out. Our friends, families, colleagues, and neighbors will miss out on all we can contribute to our communities, both socially and economically. This isn't just about making treasured holiday memories with loved ones, although that is a beautiful part of the human experience. It's also about fostering a country where all of us can grow older, assured by the notion that we will always have a place to call home. Thank you.

The CHAIRMAN. You have a choice. It's cold in New Jersey. It's not so bad in Florida. It's pretty nice right now. Now, we'll go to questions. Let's start with Senator Moody.

Senator MOODY. Thank you, Chairman Scott, and I think Florida is experiencing a massive influx at the moment. He continues to be a cheerleader, having been the former Governor and contributing

so much to its success now and why so many people want to move there, but we will always welcome others.

In fact, we are known as the Sunshine State but we're also known as the Silver State. For good reason, almost a quarter of our population is considered seniors, and that is why on this small committee you have the two Florida Senators both participating and engaging on these very important issues. They affect so many of Floridians and we think it's important and we welcome a Floridian with us today.

We're so glad to have you, so proud of you and your career, but not just what you accomplished on the field, but certainly what you have done for your community since. Such a benefit to the State of Florida and those that call Florida home, so, thank you for being with us. Aging in place is so very important and we know that the Older Americans Act in many ways helps with stability and meaningful assistance to families who are often stretched thin by caregiving responsibilities.

I think a hearing like this is so very important. I thank Chairman Scott and Ranking Member Gillibrand for convening this hearing focusing on specific programs, yes, but also overall on the Older Americans Act and how it provides critical support to seniors and their families. It also helps build community for a growing number of seniors in America who are living alone.

Some of the statistics, according to the National Council on Aging show that 28 percent of adults, 65 and older live alone, and as we approach the end of the year, we're reminded that many seniors will face this holiday season in isolation, and so, we want to ensure that the Older American Act continues to offer programs that help older adults strengthen their connections and build supportive communities so this doesn't have to be the case.

With that said, I have a few questions for our witnesses, and certainly, listening to your testimony, I'm kind of going to go off. I planned some subjects I wanted to talk about, but I was really interested in your testimony, Mr. Resendez. You were talking about how there's kind of a flop of where we should be prioritizing, where we're focusing our resources.

Right now, I believe you have to have a waiver to stay at home, and you were commenting on some proposed legislation specifically by Senator Scott regarding a tax credit. Can you tell us would any of those concerns be addressed by either the proposed legislation and if not, what would you recommend for Congress to address to kind of right size that approach?

Mr. RESENDEZ. Absolutely. One of the key things to your question around Senator Scott's legislation is the immense financial strain that family caregivers face or nearly 50 percent of family caregivers report experiencing at least one negative financial impact due to caregiving. Out of pocket costs conservatively due to caregiving is around $7,000 a year, and a lot of those expenses are not tax deductible.

Anything we can do for the tax code to better recognize the contributions and expenses associated with caregiving can help to alleviate some of those financial strains that family caregivers face, and then on the imbalance, what we see is an imbalance between

home and community-based spending at the state level and spending on institutional care.

There are examples where states are making efforts to set targets for rebalancing dollars toward more or less costly home-based care versus institutional care, so, there are options to explore, to rebalance that spending at the state level.

Senator MOODY. I know there are many of us that are pushing to re-up the Older Americans Act. I've co-sponsored that, I know. Both our Ranking Member and our Chairman are pushing for that. Are there specific things within that legislation that would address that imbalance?

Mr. RESENDEZ. The Older Americans Act as Alison highlighted greatly compliments home and community-based services. Fully funding and reauthorizing the Older Americans Act, increasing funding for the Older Americans Act. One of the things that we see in our data is between 2015, in 2025 we've seen a nearly 50 percent increase in the number of family care. It's 20 million more family caregivers.

Senator MOODY. What was that span that you were saying that increased by——

Mr. RESENDEZ. Ten years.

Senator MOODY. Ten years.

Mr. RESENDEZ. Ten years. Twenty million more caregivers in ten years. Yet, funding for the Older Americans Act and the National Family Caregiver Support Program specifically has remained relatively the same. The demand has increased significantly.

Senator MOODY. Wait, in your testimony though, you mentioned that you believe, if we took away the incentives that would push people into institutional care as opposed to at home caregiving, that you believe we might even be able to save money by doing that, because I think you said, and I could be wrong, that it's twice as costly to care for someone in organ institution setting versus being at home, so, with this rise in demand, are you saying that we could still save money per person if we were to shift those resources to in-home caregiving?

Mr. RESENDEZ. Absolutely. Helping folks provide care in their homes for longer enables us to save on things like the cost of institutionalized care, the cost of ER visits, so, when we support people providing care in the home, we can save money over the long term. We've seen that within the Older Americans Act.

For example, one of the things that we've seen from research for Older Americans Act programs like the National Family Caregiver Support Program in respite, is that family caregivers report that when they have that support, they can provide care for longer durations.

Senator MOODY. We may be able to mitigate the increased costs associated with the increased demand 50 percent more in a decade by shifting that to more in-home care?

Mr. RESENDEZ. Absolutely.

Senator MOODY. Thank you, Chairman.

The CHAIRMAN. Thank you, Senator Moody. Senator Kim.

Senator KIM. Thank you, Chairman. Thank you to the four of you for coming on out here. Ms. Barkoff, I'd like to bring you in on this conversation. Just given your background here, in your testimony

you stated home and community-based services include a wide range of care and support that neither private health insurance nor Medicare even cover.

Medicaid funding allows for services to exist and ensure people can comfortably age in place. Yet there are lots of concerns about Medicaid cuts and I guess I wanted your thoughts on this. Could you share how cuts to Medicaid can lead to devastating impacts for home and community-based services and what consequences this would have on programs that serve older adults and people with disabilities?

Dr. BARKOFF. Thank you, Senator Kim for that question, and as you mentioned, the primary funder and the way we are able to help keep the majority of older adults and people with disabilities in their own homes is through the Medicaid funded Home and Community-Based Services Program. States must have balanced budgets and we have seen historically that despite the huge demand for more home and community-based services, that when budgets are reduced, states, the first thing to go are optional services.

As my colleague, Mr. Resendez spoke about the fact that institutional care must be provided to anyone who meets that level, but if you want to choose to get in-home care, you have to sit on a waiting list. What we saw, actually, I conducted a study with other researchers about what states did during the Great Recession when we saw cuts and every single state cut home and community-based services around the 2010 to 2013 timeframe, despite wanting to be able to serve more people.

As states are beginning to look at their State Medicaid budgets, implement new laws, it's very, very important for the aging and disability communities to make sure people understand it is a pennywise and a pound foolish to make those kinds of cuts.

Senator KIM. As we're thinking about strengthening the home and community-based services, we also need to be addressing the workforce shortages that limit access to those services, so, the administration for community living, ACL, is critical component of achieving that, which is why it's so critical that it stays intact.

From your experience Ms. Barkoff with ACL, could you share what federal strategies would be most effective to support recruitment, training, and retention in the direct care workforce?

Dr. BARKOFF. I was very proud that during the time that I was leading ACL we really heard from stakeholders about the importance of strengthening the direct care workforce and launched the Direct Care Workforce Strategy Center. It's very critical to work directly with states on how we can improve these jobs.

We need to have better pay, we need better opportunities to advance in these careers and we really need to bring respect to these jobs. It's critical that as states are implementing these new rules, we are already starting to see cuts in rates to providers, which translates to even lower rates to direct support professionals and direct care workers.

If someone can get paid more working at Target or at McDonald's than doing this incredibly important but not well-paid work, the shortages that we have will be so much worse.

Senator KIM. Yes. Ms. Ladau, I wanted to just bring you in on this as well. You said ″Without access to HCBS and without efforts to prioritize housing and communities that work for everyone, people with disabilities and older adults will all too easily be pushed out of their homes.″ You also shared the risk you are taking as well by not applying for Medicaid due to asset limits being so restrictive.

I guess I wanted to ask you, how should Congress address the reality? Even with HCBS, many people with disabilities cannot benefit from these programs because of a lack of readily accessible housing and the financial reality that qualifying for HCBS makes it difficult to rent or buy a home?

Ms. LADAU. Thank you so much for this question, Senator Kim, and as a newer resident of your state who is currently in the process of searching for a home, I really do appreciate the opportunity to talk about this because people with disabilities are so often trapped in this catch 22 of wanting to be able to live at home and thrive in their communities, but then facing the significant red tape that comes with getting the supports and services that they need.

For me, I faced the quite frankly, impossible choice of do I stay on these life sustaining Medicaid services or do I recognize that the asset cap is holding me back and take a flying leap, quite frankly, to leave this program. It is an unfair choice that no one should have to face.

I really want to name that this is not a choice that anyone should have to make, but the answer is not to cut funding for HCBS, it's actually to make economically savvy policy choices that would first of all focus on incentivizing accessible housing stock and raising the asset limit for Medicaid.

Right now, the asset limit, which I mentioned in my testimony, is $2,000, that hasn't been adjusted for inflation, that hasn't been adjusted since before I was born, so, when you think about that, I mean, that alone is reason enough to deter people from wanting to pursue a career, to pursue finding a house because they're stuck by this asset limit.

The other thing I want to name is I did a little research and double checked and there's a study from 2023. The Kaiser Family Foundation found that the cost of long-term institutionalized care was around $11,000 more expensive than HCBS for Medicaid beneficiaries, so, ensuring policies that complement rather than contradict each other just makes good financial sense.

Senator KIM. Thank you. With that, I'll yield back Chairman.

The CHAIRMAN. Thank you, Senator Kim. Mr. Offerdahl, what role do local partnerships such as nonprofits or faith-based groups play in extending the reach of OAA services?

Mr. OFFERDAHL. Okay. Nonprofits play a huge role specifically this year in the fourth quarter, our Hand-Off Meals for Seniors kicked off a campaign for volunteer delivery drivers. We find that volunteers coming, especially through faith-based organizations like churches and synagogues really have a heart for people and to serve them, not only to deliver them food.

Our efforts were pretty strident. Our goal was 150, we got to about 35 but it isn't over, and we're going to continue to work hard

on that because we find that our paid delivery drivers engage. They do wellness checks, but they have a delivery that has to go onto the next house.

Volunteers really are the ones that are looking for a relationship, a connection with our seniors, and they have the ability to come in and just address and look for those concerns in the environment of the home, maybe appliances or things that concern them with the behavior or the acuity of maybe their seniors, and then refer them back to our aging district. That type of connection is so much more valuable.

Volunteers are huge part of that. Again, our faith-based agencies that hopefully provide most of those will becoming stronger and stronger, and it takes a while. We've been in this for a year and a half going on two and we've got another three years, so we really want to build that up.

The CHAIRMAN. Thank you. Mr. Resendez, what local approaches other than congregate meals have been most successful in reducing social isolation among older adults, especially during the holiday season?

Mr. RESENDEZ. Absolutely. Through the Older Americans Act specifically, there are a range of services provided through the Aging Services Network that help to address social isolation including, and especially for family caregivers. We see in our research that one in four family caregivers experiences social isolation.

That's actually up from what we saw just five years ago, so, things like individual counseling, support groups, and training for family caregivers provided through the National Family Caregiver Support Program helps us to address that growing trend around social isolation.

The CHAIRMAN. Thank you. Ms. Barkoff, what we hear frequently about the sandwich generation concerning people who are caring for both children and aging adults, how do a OAA programs better support these families and benefit seniors who are trying to age in place?

Dr. BARKOFF. The Older Americans Act, actually, one thing people don't know about the Family Caregiver Support Program is that it supports basically any family caregiver who is caring for—who is more than 50 years old and caring for anyone other than a child with a disability.

It actually has a whole breadth of caregivers that are part of those programs, and the Older Americans Act provides supports like respite and the support groups that Jason mentioned, but it also helps families access services, so, if you are caring for a child as well as an aging parent, you may be able to take advantage of senior centers and adult day programs that can really help.

Respite care is critical to family caregivers and that combined with some of the disability programs that the ACL also funds can really provide a great compliment of programs to support all types of caregivers, including Sandwich caregivers.

The CHAIRMAN. Thank you. Ms. Ladau, what steps can local communities take to make holiday programs more accessible for older adults who are not only trying to age in place, but also have disabilities as well?

Ms. LADAU. Thank you so much for this question, and as I mentioned during my testimony, this has far reaching implications, well beyond simply celebrating the holidays, but during the holidays, people should be able to access festivities like anyone else, and first and foremost, I think about the fact that many festivities are closed to certain people simply because they cannot access their family members' homes because those homes are not accessible.

When we're thinking about how we can increase inclusion within the community, we first need to be thinking about the housing stock and how we can improve and incentivize creating accessible homes. For programming within the community, we need to be thinking about how we can do it in an accessible way.

For example, many local towns, including the one that I used to live in, have holiday shopping events where you go around, you support local businesses. It's meant to be a boon for the local economy. However, as a wheelchair user, I often cannot get into many of these local shops because they are not made wheelchair accessible, thereby excluding me from the festivities, but also excluding my wallet from the festivities.

When we're thinking about how we can create fun and accessible holiday festivities, we need to be mindful of the fact that these shops need to be accessible, not just for a Christmas shopping experience or a Hanukkah shopping experience, but all year round, and the economic impact will pay in dividends.

The CHAIRMAN. Thank you. Let me turn it over now to Senator Alsobrooks.

Senator ALSOBROOKS. Thank you so much to Chair and invite, and our Ranking Member for holding this hearing today, and thank you as well to each of our witnesses for taking time to be here. I often speak in this Committee about my own experience and I know that my experiences is so similar to so many other Americans. As a caregiver, as a member of what's known as the sandwich generation, and it is true that every single day I balance my role as a United States Senator with that of being a mother and a daughter, ensuring that my aging parents have the care they need as they navigate the health challenges that if we live long enough, we'll surely come.

Countless Americans share my story and strive to make their own family members live with dignity and access to the care they need, and yet, so many are left without the resources or necessary community support and many more seniors are without family to advocate for them or the resources they need to afford to care.

They unfortunately slip between the cracks. I just can't imagine what the average American does. I have to tell you, in my own experience, I had a really sweet moment just last night with my mother who has dementia and my father has been her caregiver now for the last couple of years.

Like so many families, it is often the caregiver who then becomes sick, and so he was recently given a really, really serious cancer diagnosis, and so it has just brought to bear the struggles that so many have with having the care they need at night and so on and so forth.

It has really—it continues to help me understand how important this is, so, I'm joined here today by tremendous advocates for sen-

iors and individuals with disabilities, including the former Assistant Secretary for Aging and Head of the Administration for Community Living under the Biden administration.

I'm also proud to introduce the Strategic Plan for Aging Act, along with Ranking Member Gillibrand, building upon the great work that my state is already doing to support community living for seniors and individuals with disabilities, and so, my first question for Ms. Barkoff is, professor, I want to just mention that Secretary Kennedy has gutted the agency that you used to lead with a reduction in force.

I would be remiss if I didn't ask you to briefly share for the record the importance of that agency's work in advancing independence for older adults and people with disabilities?

Dr. BARKOFF. Thank you so much, Senator Alsobrooks for that question. ACL is the only federal agency focused on community living for older adults and people with disabilities, and what many people don't appreciate is that ACL does not only fund and oversee and support the incredible programs that we've been talking about throughout this hearing, but it plays a critical role in coordinating across of all of HHS and the Federal Government to make sure that older adults and disabled people are considered in all policies.

As you mentioned, ACL has been significantly impacted by the reduction in force. Less than half the staff remain, the entire policy team, evaluation team, every single one of its regional staff, the grant team, the budget team, the communication team, and external affairs, and ACL is having a hard time doing what it needs to do to be able to play its critical role in supporting the aging and disability networks, and the unique role that it plays in coordinating programs.

I hope that Congress will continue to fund ACL and HHS will continue to staff ACL to be able to meet its statutory mandates and the critical role it plays in community living.

Senator ALSOBROOKS. Thank you, and you mentioned the staff cuts but there have been staff cuts in the proposed reorganization of the Administration for Community Living. As you mentioned, undermine the agency's mission to help seniors and others living with disabilities, and the Baltimore Sun reported last month as well on the disturbing proliferation of unlicensed assisted living facilities in my own state.

These facilities are housing elderly and vulnerable residents in substandard conditions, all in exchange for their social security or disability checks, and they're engaging in a practice experts called benefit or senior trafficking, and so, Professor Barkoff, you have extensive experience working both to protect seniors and individuals with disabilities and going after bad actors that abuse these populations from both your time at HHS and the Department of Justice.

Can you talk to us about how can we give states the tools to better monitor and go after these bad actors and prevent them from operating unchecked?

Dr. BARKOFF. Thank you for that question, and I also saw this report, and the abuse and neglect and exploitation in these types of unlicensed assisted living facilities, unfortunately is not limited to Maryland. It exists really across a number of states in these boarding care homes or adult care homes.

It's incredibly important, ACL plays a major role in implementing Elder Justice, the Adult Protective Services Programs, the Long-term Care Ombudsman Program, really working with states to prioritize how to identify this type of abuse and neglect, how to make sure law enforcement knows how to work with these networks.

What I can unequivocally say is when you look at and this Committee has had a number of hearings on the resources available to Adult Protective Services and Ombudsmen, it is minuscule compared to the serious abuse and neglect that is happening to older adults and people with disabilities.

Senator ALSOBROOKS. Thank you so much.

The CHAIRMAN. Thank you, Senator. Ranking Member Gillibrand.

Senator GILLIBRAND. Thank you. To Alison Barkoff, average electricity costs have risen 11 percent since January of this year, which is more than three times the rate of inflation. Families just can't keep up with the spiking costs, particularly older adults on fixed income in the winter when heating costs are necessary to keep them alive.

Approximately 2.4 million Americans rely on the LIHEAP program, Low-Income Home Energy Assistance Program just to afford their energy bills and make cost efficient repairs to their heating systems. Can you tell us what ways does LIHEAP support older adults and people with disabilities the ability to live in their community of choice? How would funding cuts to LIHEAP impact this population?

Dr. BARKOFF. As you mentioned, so many older adults and people with disabilities are living on fixed incomes and are low income, and programs like LIHEAP are incredibly important to help them be able to afford to stay in their own homes and communities. LIHEAP is a program that is targeted to the people who are most vulnerable to adverse health conditions when they don't have access to adequate cooling or heating, and the statistics based on HHS' own data is over 42 percent of LIHEAP goes to households with older adults and more than 35 percent to households with people with disabilities.

Cuts to this program can make remaining in the community and aging in place both unaffordable and unsafe.

Senator GILLIBRAND. Thank you. For Emily Ladau, this past weekend, we commemorated the 50th anniversary of the Individuals with Disabilities Act or the IDEA. The IDEA guarantees students in preschool and K–12, a free and appropriate public education at the least restrictive setting possible. The Department of Education plays a crucial role in making this guarantee a reality for millions of students across the country, including 550,000 students in New York State.

However, I was alarmed at the targeted reduction and forced notices that were sent to the Office of Special Education Programs within the Department of Education during the government shutdown and they sent a letter imploring the administration to immediately reverse these RIF notices.

Ms. Ladau, can you talk about how important accessibility and reasonable accommodations are for students K–12 and how cuts to

the Department of Education will impact our students with disabilities?

Ms. LADAU. Thank you, Senator Gillibrand. First of all, for your advocacy to ensure that access to education for all children remains intact, and also, for bringing up this very vital topic, and I really want to be sure to draw a very clear connection between this question and the topic of community living.

Because being able to live at home and be the beneficiary of HCBS is such a vital part of the equation that actually allows kids with disabilities to attend school, which was true for me because I grew up attending a local public school and I had a section 504 plan that secured the reasonable accommodations that I needed to fully participate and succeed in school.

Both IDEA and also section 504 of the Rehab Act are really essential protections for students, and the Department of Education plays such a vital role in enforcing these laws and distributing resources, so I, like you, have grave concerns about these efforts to dismantle the Department of Education through reductions in force, funding cuts, and also relocation of key programs like moving the Office of Special Education Programs to exist under HHS.

Which I do believe could send this country backward toward segregating students based on diagnosis rather than expanding educational opportunities, so, I'll just wrap up by saying that I believe the changes that this administration is currently pushing are not going to, as they claim, ″Improve outcomes by empowering parents, states and communities,″ but instead threaten the futures of more than seven and a half million students with disabilities who, like all students should have access to education as a pathway to graduation, college or career training, employment, and of course economic opportunity in the community. Thank you.

Senator GILLIBRAND. Thank you. For Mr. Resendez, today we have highlighted the services and supports that older adults and people with disabilities need to live independently. These services and supports are often provided by direct care workers who assist older adults and people with disabilities, with activities of daily living, such as dressing, and bathing in home settings.

Unfortunately, these workers may face systemic challenges and turnover in this workforce approaching 80 percent, they already faced this in 2023. More recently, the Department of Labor has published a proposed rule that would exclude home care workers for minimum wage and overtime pay protections.

It's why I'm introducing my Domestic Workers Bill of Rights Act next week to patch the flaws in existing labor laws to ensure that workers who provide home and community-based services and other domestic workers have the same rights and dignity as workers in other professions. Could you please speak to the importance of the direct care workforce and to both home and community-based services and elaborate on some of the challenges this workforce faces and how protections like those outlined in my domestic workers bill of rights could help?

Mr. RESENDEZ. Thank you for the question, Senator Gillibrand. One thing is clear; family caregivers rely on direct care workers. We see this in our research. One third of family caregivers use paid help, direct care workers, home health aides to help support their

care recipients. This partnership between family caregivers and direct care workers is essential.

Without adequate paid help, family caregivers will shoulder more intensive responsibilities. With 24 percent already providing 40 or more hours of care a week. Our research shows that 28 percent of family caregivers now have difficulty finding affordable services like in-home healthcare up from 22 percent in 2015.

Anything that we can do to stabilize the direct care workforce benefits not just these essential workers, but also millions of family caregivers who rely on them as being part of care teams to deliver care in the home sustainably for long periods of time.

Senator GILLIBRAND. Thank you. Thank you, Mr. Chair.

The CHAIRMAN. Thank you, Ranking Member. Mr. Offerdahl, what lessons from the Broward County pilot could be replicated nationwide to modernize home delivered meals?

Mr. OFFERDAHL. Great question. One of the things that our district did was our FPD for multiple service providers and the four service providers that got awarded, two of them were restaurant centric service providers, two of them were catering service providers. The combination kind of covers all the gamuts.

It's a great combination. Personally, I think one of each category is probably more manageable by the aging district but giving that the catering can do customized, they can do kosher, they can do a lot of different things, the restaurants can do on time production with fresh quality food. It provides a great choice, a specialization of both service providers, but a choice to the senior that I think they need, right?

The agency for a senior is critical in-home care, but in also the choice of food, so, I think that alone, at the same time the restaurant providers can contract out with other restaurants for specific meals to create variety. We had a relationship with Padrino's Cuban cuisine, that type of fresh quality food and Broward County really connects, so, the ability to do that along with others, it has to be—it has to be profitable for the for the subcontractor, but they often will discount their profits to be part of a community engagement program that brings a lot of awareness and charity to them.

I'm very excited because I have another three years to kind of test this model and continue to improve it, and at the end of the day, I totally believe that the seniors who are home bound will receive the benefit of that effort.

The CHAIRMAN. That's great. Mr. Resendez, how would a targeted tax credit for adults caring for aging parents help families manage the pressures associated with multi-generational living?

Mr. RESENDEZ. We see one of the ripple effects of family caregiving is financial impact. Nearly 50 percent of family caregivers experiencing at least one negative financial impact. Two thirds experiencing two or more negative financial impacts, including going into debt, taking out high interest rate, credit cards and loans.

Anything we can do to recognize the economic value that family caregivers contribute and the economic cost of caregiving on families is a step in the right direction. We know that family caregivers spend on average $7,000 or more on out-of-pocket expenses to support caregiving. Think about things like adult diapers and things

to make your home more suitable for caring. Those things are not tax deductible, so, targeted tax credits can help us in the tax code better recognize and value the contributions of family caregivers, particularly those within intergenerational household.

We know that 40 percent of family caregivers are living with their care recipient. That could be a grandparent taking care of a grandchild. It could be a son caring for his spouse or his wife, or his grandmother, or mother with a serious illness or a functional limitation.

The CHAIRMAN. Thank you. Ranking Member Gillibrand.

Senator GILLIBRAND. For Alison Barkoff. Today, we have highlighted how we can support older adults and people with disabilities so that they can live in their communities. One way to enhance supports and services for older adults is multi-sector plans for aging. These plans are state led cross-sector strategic planning resources that help states transform the infrastructure and coordination of services for older adults and their families.

Today I will reintroduce my Strategic Plan On Aging Act. The Strategic Plan for Aging Act creates a grant program under the older Americans Act to incentivize and support states to create their own multi-sector plans for aging and for people with disabilities. Professor Barkoff, could you speak to how a multi-sector plan for aging can improve supports and services for older adults? What benefits and of including direct input from older adults and people with disabilities in the development of these plans?

Dr. BARKOFF. Thank you for the question and thank you for your leadership here. As we've talked about today, it takes a lot of different supports and services for people to age in place and stay in the community. That includes community-based services and affordable housing, and accessible transportation, and affordable healthcare.

Those services and supports cut across so many state and local agencies, sectors, providers, and types of advocates, and comprehensive and coordinated planning is absolutely critical, and that's why more than a dozen states have begun this comprehensive planning through multi-sector plans on aging. I so appreciate your bill and in your comments, you're highlighting that the experience of people with lived experience is critical.

They are best positioned to be able to say what works and doesn't work in the current system and where gaps are. It's also incredibly important and we're seeing more and more with states that people are including the disability community in those efforts. As we've heard today, the largest population of disabled people is older adults with disabilities, and the common needs and priorities cut across so many areas.

Finally, I'll just mention when I was at ACL, seeing the huge momentum, we worked on developing a strategic framework for a national plan on aging and we tried to model exactly what we were seeing in states bringing together agencies and departments with expertise, so, thank you again for reintroducing that act that I think will give a lot of momentum and resources to existing state efforts and really encourage that important aging and disability partnership.

Senator GILLIBRAND. Thank you, Alison. Emily, I want to ask about some of the challenges during the holidays that people with disabilities are often facing. First of all, accessibility for air travel. In 2013, 11,527 wheelchairs and scooters were mishandled by airlines. This mishandling can lead to costly repairs and leave wheelchair users without the technology they need to get around.

For many people, it's not just losing a chair, it's losing their independence. Chairs are extremely expensive. That's why I was disappointed to see the Department of Transportation was delaying the implementation of regulation that would address these harmful trends, so, can you discuss the importance of accessible transportation, especially accessible air travel and how delaying implementation of this regulation and impact will impact people with wheelchair users?

The second question I have is about web accessibility, because obviously when you're planning any time to go home, you use the internet to book your air travel, you use the internet to find hotels, you use the internet to do everything, and we've really not met our requirements of making the internet accessible at all. In 2022, this Committee released a report that found web accessibility failures throughout the Federal Government, including at agencies such as the Centers for Disease Control and Prevention in the Department of Veterans Affairs.

The VA's own reporting said approximately 90 percent of websites at the Department of Veterans Affairs were not fully accessible for people with disabilities as required by law, so, maybe just touch on these two things and anything else you want to bring up?

Ms. LADAU. Thank you, Senator Gillibrand. I am happy to talk about these issues. I want to first actually address the web accessibility part. This is very much intertwined with travel because you often need to book your travel through a website, and if that website is not accessible, it immediately precludes you from being able to book your travel independently, and this is an issue not just for people with disabilities, but for older Americans who may struggle to keep up with ever evolving technology.

Think of engaging with video content, think of watching a movie with captions, accessibility benefits, everybody. It just makes sense to implement accessibility and it makes the user experience easier for everyone, and when it comes to air travel, goodness knows, we need all of the improvements on experience we can get. I will say that I am one of the 11,000-plus people who has had my wheelchair damaged in the course of a given year.

I'm going to be very honest that it made it very difficult for me to go visit my grandmother before she passed away. She lived in Florida. I was not able to go see her because I was so afraid of my wheelchair breaking on an airplane that I instead chose not to make that trip because it was going to be so incredibly challenging knowing that my wheelchair had previously been broken.

When I flew across the United States from New York to Oregon, I found that my joystick had been completely sheared off when I landed and had to hold it together with duct tape and with zip ties, and I would just ask everyone to imagine if that was somebody's legs that were being held together with duct tape and zip ties.

All of that is to say that whether you are visiting a loved one, whether you are taking a holiday trip, whether you're a grandparent using a scooter who just wants to enjoy Disney World with their grandkids, you should be able to travel knowing that your mobility equipment will arrive intact, and this is an essential form of community living because it is indeed participating in the community.

It's not just the right thing to do, it also makes economic sense to keep people moving around the world safely. Thank you.

Senator GILLIBRAND. This question is for Jason. Thank you for discussing the Family Act in your opening statement, the Family Act would create a national family and medical paid leave program. Specifically, it would establish 12 weeks of paid leave for serious medical and family events, including the need to care for a loved one.

Can you go into further detail on why the Family Act is necessary? What kind of hard choices are American families forced to make when paid family leave is unavailable? Does the National Alliance for Caregiving have any caregiver stories that highlight those challenges?

Mr. RESENDEZ. Absolutely. Thank you so much, Senator Gillibrand. First, I want to say that there are 35 million family caregivers who provide care while working at the same time, so, without paid leave, these millions of family caregivers face impossible choices between providing essential care for loved ones, including older adults with serious conditions like Alzheimer's or cancer, or maintaining their financial security, and according to our data, they often sacrifice both, leave jobs, deplete savings, and take on debt with long-term consequences for their own retirement security and economic stability.

In fact, half of all working caregivers report going in late, leaving early or taking time off to provide care. We heard from one such family caregiver, Marcy, a family caregiver in Kansas, who provides care for both her mother and also her grandson, who is ultimately forced to leave her job because of her caregiving responsibilities.

She told us, ″They needed more time than what I had, and I couldn't take any more time off work. I was working 60 hours a week and coming home and doing everything too, to lose that income, it was a big hit.″ If we don't do more to help family caregivers balance both the care that they need to provide and the work they want to do, we're going to see more and more examples like Marcy's.

The CHAIRMAN. One, the Ranking Member and I would like to thank everyone for being here today and for the work you all do to support older Americans and the families who care for them. Aging in place is not only what many older Americans want, it's also better for their health and better for their families. The pressures on the sandwich generation are real and they'll grow heavier this time of year. Community-based support and OAA programs help lighten that burden and keep families strong. For 60 years, the OAA has been the backbone of critical services that promote independence and social connection for older adults.

That is why this Committee remains committed to working in a bipartisan way to re-authorize the OAA and strengthen programs that help seniors age in place. I look forward to continue to work with members on this Committee.

If any Senator has additional questions for the witnesses or statements to be added, the hearing record will be open until next Wednesday at 5:00 p.m.

The CHAIRMAN. I thank each of you.

[Whereupon, at 4:27 p.m., the hearing was adjourned.]

APPENDIX

Prepared Witness Statements

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

PREPARED WITNESS TESTIMONY

John Offerdahl

Chairman Scott, Ranking Member Gillibrand, and Members of the Committee - It is an honor to speak with you today about an issue affecting millions of older Americans: ensuring that seniors can age in place with dignity, safety, independence, and meaningful human connection. This is important every day of the year, but especially during the holiday season, when social isolation and food insecurity among older adults rise sharply.

Introduction

As mentioned, my name is John Offerdahl. I became a proud resident of Broward County 40 years ago, when drafted by the Miami Dolphins in 1986. I spent my entire eight-year NFL career in South Florida, and for 36 of those 40 years, my wife Lynn and I have owned and operated regional restaurant chains, which we continue to run today. Throughout these decades, we have remained deeply involved in charitable work across South Florida-including through our Offerdahl's Hand-Off Foundation.

Background and COVID Experience

Now you ask, how does an NFL linebacker become an Older American Act Home Delivered Meal service provider for the Area Agency on Aging of Broward County? Let me tell you the story!

The Hand-Off Meals for Seniors program was born during the onset of the COVID pandemic, when Miami Dolphins owner Stephen Ross reached out to several of his Miami Dolphins alumni players, who were also restaurateurs, to help produce & deliver $1MM of weekly emergency meals to families and seniors in the neighborhoods surrounding Hard Rock Stadium. With additional support from generous partners, we delivered more than one million meals across Broward County - many for homebound seniors.

In the years that followed, emergency COVID funding through the Area Agency on Aging of Broward County and the Florida Department of Elder Affairs, allowed us to continue this work. By 2022, our team had delivered hundreds of thousands of FRESH meals to vulnerable seniors & families who needed them most.

These experiences revealed a truth still urgent today: homebound seniors are a hidden population, often forgotten, isolated, and deeply in need of dependable nutrition and meaningful human contact.

A New Model for Home-Delivered Meals

The success of this effort led the Area Agency on Aging of Broward County-under the leadership of current CEO, Charlotte Mather-Taylor-to rethink its 48-year Older American Act home-delivered meals program. Rather than awarding one contract to the lowest-cost frozen meal provider, the Agency on Aging awarded competitive contracts to multiple service providers. This ultimately offered variety and choice to Broward County homebound seniors.

Our foundation's program, Hand-Off Meals for Seniors, was selected in 2023 for a six-month pilot contract based on our proven ability to deliver fresh, restaurant-quality meals paired with compassionate, relationship-centered service. Seniors responded with overwhelming appreciation, and on January 1, 2024, our program was one of four service providers in Broward County awarded a five-year Older American Act Home Delivered Meals contract.

Today, Hand-Off Meals for Seniors is the leading service provider in Broward County delivering more than 4,500 fresh home-delivered meals and wellness visits every week to over 450 homebound seniors across Broward County.

Why the Older Americans Act Matters

Broward County reflects the future of our nation. Florida has one of the highest concentrations of seniors in America, and Broward's population of adults over 85 is projected to increase by 169% over the next 25 years.

Vulnerable, homebound seniors often live alone, without family, caregivers, transportation, or the ability to shop and cook making the need for support so huge that the Area Agency on Aging maintains a long waiting list underscoring the urgent

need for strong, sustained investment in the Older Americans Act.The choice between aging in the community or entering institutional care often hinges on access to basic supports.

Allow me to highlight five ″Basic Support″ takeaways we have learned in Broward County for the Committee to consider:

1. Healthy competition among meal providers drives better quality, service and outcomes - Providers like us are food-centric-not large industrial frozen-meal brokers. Most meals we deliver offer FRESH salads, sandwiches, fruits, and vegetables vs institutionalized frozen tv meals. While FRESH ingredients & real time production are more expensive, local production in scattered restaurant locations across Broward County create decentralized pickup points that make the system efficient and sustainable.

2. Healthy competition among meal providers inspires innovation and efficiencies that mitigate costs - Providers can leverage a restaurant's purchasing power, fixed costs, and community commitment to provide high-quality meals at sustainable rates-discounting profits in service of the community-based mission.

3. Healthy competition among meal providers invigorates stronger public-private partnerships - Funding partnerships have expanded, supported by organizations like the Jim Moran Foundation, Community Foundation of Broward, Miami Dolphins Foundation, and Publix Charities to help cover the gap between public funds & the elevated costs of restaurant quality, FRESH meals.

4. Healthy competition among meal providers engages the soul - A meal in our model is never just a meal. Delivery drivers visit the same seniors each week, building trust and companionship. These visits are also the moments when someone notices memory decline, hazardous living conditions, or failing appliances.

5. Healthy competition among meal providers gives seniors the CHOICE! - Seniors retain personal for their choice of meals!

Conclusion

This is the kind of improvement we all hope to see from government programs: invigorated partnerships, better outcomes, more choice, and an ″age in place″ option for seniors that will cost less and be more innovative, responsive and personal, than institutionalized care. Healthy competition among meal providers is good for the body & soul of our aging in place seniors. during the holidays and beyond!

At every level, this work is a public-private partnership-and the Older Americans Act is the backbone of the team. As Coach Shula taught us, ″In life as in football. it takes a team.″

Chairman Scott, Ranking Member Gillibrand, and Members of the Committee: aging in place is not merely a policy objective-it reflects who we are as a nation. The Hand-Off Meals for Seniors program demonstrates what becomes possible when FRESH, high-quality nutrition is paired with consistent human connection and allowed to compete for the body & soul of our senior.

I invite every member of this Committee to visit us in Broward County, meet our volunteers, talk with our seniors, and join my wife and me for one of our weekly meal deliveries. I give you my promise-you will be inspired!

Thank you for your time, your leadership, and your commitment to strengthening the golden years of America's older adults.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

PREPARED WITNESS TESTIMONY

Jason Resendez

Good afternoon, Chairman Scott, Ranking Member Gillibrand, and Members of the Committee:Thank you for the opportunity to testify about the role that family caregivers play in enabling older adults to age in place, in their community.

My name is Jason Resendez, and I am the President and CEO of the National Alliance for Caregiving, a national organization focused on transforming how our nation values its more than 63 million family caregivers.

For nearly 30 years, we've documented and amplified the experiences of family caregivers-their challenges, hardships, and joys-while measuring our country's progress in supporting their critical work.

We are living through a profound demographic shift. Every single day, roughly 10,000 Americans turn 65. Medical advances mean people are living longer than ever.[1]

This is a tremendous achievement, but it also presents new challenges-challenges that largely fall on the shoulders of our country's family caregivers.

Today, these Americans make up the backbone of our nation's long-term services and support system.Family caregivers are our neighbors, our friends, and our family. They fill our schools, workplaces, and places of worship.

And as we head into the holidays, many Americans will be talking about caregiving issues with their family and friends. It has become a "kitchen table" issue.

For those caring for older relatives, you might hear someone talk about Dad's recent fall, his time spent in the hospital and then his discharge home where he suddenly needs someone to help him bathe, dress and prepare meals.

Change the name and the illness or health incident, but this is going on daily, across America, and family caregivers are the ones who step up and do the hard work - often on a moment's notice.

The Growing Need

And their numbers are growing. According to new data from the National Alliance for Caregiving and AARP's landmark Caregiving in the US 2025 research, 63 million or one in four Americans is now a family caregiver-representing a nearly 50 percent increase since 2015.[2]

That's 20 million additional caregivers in just one decade.

This surge directly mirrors our aging population and a critical reality: 70 percent of older Americans will need some form of long-term services and supports during their lifetime.[3]

Understanding who provides this care is essential. Sixty-one percent of family caregivers are women and 38% are men, with an average age of 51. The vast majority-89%-care for relatives, most commonly a parent or parent-in-law (47%), and nearly half support someone age 75 or older. Twenty-nine percent are "sandwich generation" caregivers responsible for both young children and older adults, with African American and Latino American caregivers more likely to be in this dual role.[4]

Often, this care occurs within intergenerational households-40% of caregivers live with their care recipient, a figure that rises among lower-income caregivers, men, and caregivers of color. The caregiver population reflects America's diversity: 61% are non-Hispanic white, 16% Latino American, 13% African American, and 6% Asian American/Native Hawaiian/Pacific Islander. One in five caregivers lives in a rural area, and nearly one-quarter are juggling care for multiple recipients simultaneously.

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[1] U.S. Department of Health and Human Services, Aging. Washington, D.C.: U.S. Department of Health and Human Services. Available at: https://www.hhs.gov/aging/index.html

[2] AARP and National Alliance for Caregiving, Caregiving in the US 2025. Washington, D.C.: AARP. July 2025. Available at: https://www.caregivingintheus.org

[3] ACL Administration for Community Living, "How Much Care Will You Need?" Washington, D.C.: U.S. Department of Health and Human Services. Available at: https://acl.gov/ltc/basic-needs/how-much-care-will-you-need

[4] Op. cit.

Across these demographics, caregiving now requires greater commitment-both in duration and intensity. Thirty percent of caregivers have been providing care for five or more years. They spend an average of 27 hours per week on caregiving duties, with nearly one in four putting in 40 or more hours-equivalent to a full-time job, and for 61%, this comes on top of paid employment.

Family caregivers deliver comprehensive, complex support that would otherwise require teams of paid professionals. Seventy percent monitor their loved ones' health conditions and adjust care accordingly. Nearly two-thirds communicate directly with healthcare providers, serving as the crucial link in care coordination.

More than half perform complex medical and nursing tasks such as administering medications, managing special diets, and providing wound care. Many provide around-the-clock support for the people they love. Yet only 22 percent of caregivers performing these complex medical tasks received any training. When training is provided, 96 percent feel it prepared them well highlighting both the gap and the opportunity.

As one caregiver, Maylia from California, shared: ″I had to give up a prosperous career and took jobs to work around their schedule. I took a 90% pay cut and lived out of my savings, which has been depleted.″ She went on to say, ″Being a caregiver is the hardest role... You are playing three or more roles: taking care of your family members, the house, yourself, your job.″[5]

The Foundation of Our Healthcare System

As Maylia's story makes clear, family caregivers are essential to healthcare delivery. They enable something Americans overwhelmingly desire: the ability to age and receive care at home, in their communities, surrounded by what's familiar and meaningful to them.

This matters for two fundamental reasons:

First, dignity and freedom. When people remain in their own homes, they maintain control over how and when they receive care, and importantly, who provides that care. These choices profoundly impact quality of life.

Second, basic economics. Annual nursing home costs average approximately $120,000, compared to roughly $44,000 for 30 hours of weekly home-based care at $30 an hour.[6] Put simply, the cost of supporting one person in a nursing facility could support more than two people at home, and when family caregivers provide a substantial portion of this care-with appropriate support-the savings to Medicaid grow exponentially.

Congress recognized this reality nearly 25 years ago when it amended the Older Americans Act to create the National Family Caregiver Support Program. This program acknowledges that supporting the caregiver is inseparable from supporting the person receiving care. Yet funding has never matched the growing need even as caregiver numbers have surged by 20 million in a decade.

The Crisis of Strain

Despite their heroism and economic value, family caregivers face a growing crisis. Nearly two-thirds experience moderate or high emotional stress, 45 percent report physical strain, and nearly half have experienced at least one negative financial impact. One-third have stopped saving entirely. Nearly one in four report feeling alone, a figure that has increased since 2020.

Strikingly, 56 percent of caregivers felt they had no choice in taking on their role, with profound consequences: these caregivers experience nearly twice as many poor mental health days as those who felt they had a choice.

Over the past decade, National Alliance for Caregiving data show that family caregivers are struggling more-and for longer-than ever before. Black, Latino, rural, and other underrepresented communities - especially women - disproportionately bear these hardships.

The financial toll is particularly acute for these communities. African American and Latino American caregivers are significantly more likely to take on debt, use up savings, and be unable to afford basic expenses like food. Lower-income caregivers, those already least able to weather financial storms, are hit hardest, with 28 percent unable to afford basic expenses compared to eight percent of higher-income caregivers.

Seven in ten working-age caregivers balance employment with caregiving responsibilities. Half experience work disruptions-arriving late, leaving early, or taking

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[5] Op cit. p. 36 and p.39.

[6] Genworth Financial, Inc., Genworth and CareScout Release Cost of Care Survey Results for 2024. Richmond, VA: Genworth Financial, Inc.; March 2025. Available at: https://www.businesswire.com/news/home/20250301584443/en/Genworth-and-CareScout-Release-Cost-of-Care-Survey-Results-for-2024.

time off. Working caregivers actually report feeling more isolated than non-working caregivers and face greater financial strain.

While access to caregiver-friendly workplace benefits has improved, salaried workers enjoy significantly better access than hourly workers creating an equity gap that policy must address.

This is where Older Americans Act programs become essential. The National Family Caregiver Support Program-a cornerstone of the OAA-provides the very services caregivers need most: respite care, counseling, training, and information services. Delivered through our national aging network of Area Agencies on Aging, these programs offer a lifeline to caregivers struggling to manage alone.

Dianne, a family caregiver from Green Bay, Wisconsin, put it this way: ″The Older Americans Act helped me, the primary caregiver, have a few precious moments to myself to recharge. It provided relief to an already tight budget stretched thin with additional supply costs. I cannot imagine what other families are having to sacrifice in order to care for their loved ones.″[7]

[7] National Alliance for Caregiving, Dianne's Story. Washington, D.C.: National Alliance for Caregiving; n.d. Available at:https://www.caregiving.org/care—stories/dianne-2/

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

PREPARED WITNESS TESTIMONY

Alison Barkoff

Good afternoon, Chairman Scott, Ranking Member Gillibrand, and Members of the Committee. Thank you for inviting me to participate in today's hearing.

My name is Alison Barkoff. I have more than 25 years' experience in disability, aging, and community living policy. I am the Hirsh Health Law and Policy Associate Professor and Program Director at George Washington University.[1] I previously served as the Acting Assistant Secretary for Aging and Administrator of the Administration for Community Living and held leadership roles related to community living in the Centers for Medicare & Medicaid Services, Departments of Labor and Justice, and several non-profit organizations. I also bring my lived experience as a sibling of a brother with intellectual disabilities to my work.

Preference for and Benefits of Community Living

The vast majority of older adults and people with disabilities want to live in their own homes and communities instead of in nursing homes or other institutions.[2] It allows them to remain with their families and friends, participate in community activities, work or volunteer, and age in place. With appropriate supports, people are generally happier and healthier in the community.[3]

Supporting an individual in the community costs a fraction of providing care in a nursing home or other institution.[4] In addition, federal laws and the U.S. Supreme Court have recognized that people have a right to receive services in the most integrated setting appropriate to their needs.[5]

There has been strong bipartisan support for policies, programs, and services that help older adults and people with disabilities live in the community and age in place, such as the Older Americans Act (OAA) programs and the Money Follows the Person program that helps people transition from nursing homes back to the community. The demand for community living is expanding exponentially, with more than 10,000 people turning 65 every day and a growing population of disabled people living longer (often with aging caregivers).[6]

Supporting Older Adults and People with Disabilities in the Community

Medicaid-funded Home and Community-Based Services

Many older adults and disabled people require assistance to live in their own homes and communities. Medicaid is the primary funder of these supports, known as Home and Community-Based Services (HCBS). HCBS include a wide range of services such as home care, senior day programs or disability employment supports, respite care, family caregiver supports, and accessible transportation. Neither private health insurance nor Medicare cover these services (despite many older adults mistakenly believing they do), few people have private long-term care insurance, and most people cannot afford to pay out-of-pocket.[7]

Medicaid is a state-federal partnership, and states design their own Medicaid systems within federal law and guidelines. States must provide nursing home and other institutional services to people who are eligible because they are "mandatory" services under Medicaid law. In contrast, HCBS are "optional," meaning that states are permitted to cap enrollment in their HCBS programs. Currently there are over 600,000 people on waiting lists for HCBS.[8] A top policy priority for the aging and disability communities is to reverse this "institutional bias" in Medicaid and put HCBS on equal footing with institutional care.

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[1] I am testifying in my individual capacity and not on behalf of the university.

[2] https://www.aarp.org/pri/topics/livable-communities/housing/2024-home-community-preferences/

[3] https://acl.gov/about-community-living

[4] https://acl.gov/about-community-living

[5] See Olmstead v. L.C., 527 U.S. 581 (1999); https://archive.ada.gov/olmstead/olmstead—about.htm; https://www.ada.gov/topics/community-integration/

[6] https://www.kiplinger.com/retirement/turning-65-key-things-to-know

[7] https://www.kff.org/medicaid/issue-brief/10-things-about-long-term-services-and-supports-ltss/

[8] https://www.kff.org/medicaid/a-look-at-waiting-lists-for-medicaid-home-and-community-based-services-from-2016-to-2025/

Despite the optional nature of HCBS, states have expanded their investments in HCBS over time, with increased funding, new authorities and ″rebalancing″ funding from nursing homes and other institutional settings to HCBS programs to better match people's preferences. Nationally, 65 percent of state Medicaid long-term care spending goes towards HCBS,[9] but the percentage varies significantly both by state and by aging and disability sub-populations.[10] Continuing efforts to expand HCBS is essential to helping people remain in their community and age in place, particularly in light of the growing demand and need. Yet reductions in federal Medicaid funding to states could put optional services, like HCBS programs, at risk for cuts.[11]

Older Americans Act Programs The OAA funds a range of community-based services to help older adults, including older adults with disabilities, age in place, maintain their health, and engage in their communities. This includes personal care services, respite, transportation, family caregiver supports, and senior nutrition programs. OAA programs support one in five Americans over 60.[12]

OAA programs complement, but do not duplicate, other programs like Medicaid HCBS. OAA programs often serve individuals who are not yet eligible for Medicaid due to their level of need or financial situation or who are on HCBS waiting lists in their state. OAA programs also provide services that other programs do not cover, like family caregiver supports or meals.

OAA programs are cost effective. For example, one year of home delivered meals costs less than one day in the hospital. They also save hundreds of millions of dollars annually to other programs like Medicare and Medicaid by preventing unnecessary emergency room, hospital, and nursing home admissions; OAA programs led to nearly two million extra days living in the community instead of in hospitals or nursing homes. Every dollar invested in OAA generates $3.39 in community value and taxpayer savings.[13]

As the population of older adults continues to quickly grow, the demand for OAA-funded services has outpaced their capacity. Many programs already have long waiting lists, including one in three Meals on Wheels Providers.[14] In addition, the demand on OAA programs is expected to increase as federal funding to other programs that older adults rely upon, like Medicaid and the Supplemental Nutrition Assistance Program (SNAP), decrease.

The OAA has long had bipartisan support. In the 118th Congress, the Senate passed bipartisan legislation to reauthorize the OAA and strengthen its programs. Reauthorization of the OAA and increased investment in its programs is a top priority for the aging community and an important step to supporting older adults to age in place.

Independent Living and Other Disability Programs

Independent living programs, authorized and funded under the Rehabilitation Act, help support disabled people of all ages to live, work, and participate in their communities. Local Centers on Independent Living (CILs) provide a wide range of supports, including assistance to people at risk of entering or transitioning from institutions to the community, training on independent living skills, transportation, and assistance with finding a job or housing.[15] Other programs funded under the Developmental Disabilities Act, including State Councils on Developmental Disabilities,[16] Protection and Advocacy Systems,[17] and University Centers on Excellence in Developmental Disabilities,[18] help people with intellectual and developmental disabilities and their families in accessing community-based services. As with OAA programs, demand outpaces growing need; continued investment in these programs is essential to supporting the growing population of disabled people, including those aging with and into disability.

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[9] https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-rebalancing-brief-2022.pdf

[10] https://aspe.hhs.gov/sites/default/files/documents/ad7cf66fb2a7ae1a0bd91b288363fc71/rebalancing-ltss-medicaid-enrolled-brief.pdf

[11] https://geigergibson.publichealth.gwu.edu/history-repeats-faced-medicaid-cuts-states-reduced-support-older-adults-and-disabled-people

[12] https://www.advancingstates.org/sites/default/files/2024-oaa-roi-infographic-national.pdf

[13] https://www.advancingstates.org/sites/default/files/2024-oaa-roi-infographic-national.pdf

[14] https://www.mealsonwheelsamerica.org/news/meals-on-wheels-america-calls-for-donations-this-giving-tuesday-and-all-giving-season-long-to-ensure-no-senior-is-left-hungry-and-alone-during-the-holidays/

[15] https://acl.gov/sites/default/files/programs/2023-12/CIL—FactSheet—2023.508.pdf

[16] https://acl.gov/sites/default/files/programs/2023-12/DDCouncils—FactSheet.508.pdf

[17] https://acl.gov/sites/default/files/2025-03/protection-advocacy-factsheet-acl.pdf

[18] https://acl.gov/sites/default/files/programs/2023-12/UCEDD—FactSheet—2023.508.pdf

Affordable Accessible Housing

For many older adults and disabled people, the lack of affordable, accessible housing is a barrier to community living. A recent AARP report found that housing affordability and accessibility are a significant challenge for nearly half of older adults.[19] Less than five percent of housing stock is accessible.[20] Many older adults and disabled people pay more than one-third of their income on housing, often requiring them to spend less on food or needed medical care and placing them at risk of homelessness.[21] As a result, these populations comprise the majority of people experiencing or at risk of homelessness, with older adults being the quickest growing homeless population.[22] Supporting community living and aging in place will require increased investments in affordable, accessible housing; cuts to housing programs could force people into more expensive nursing homes and other institutional settings or into homelessness.

Multisector Plans to Support Community Living

Supporting older adults and people with disabilities to live in the community and age in place requires coordination across systems, ensuring access to community-services, affordable housing, accessible transportation, affordable healthcare, and more. More than a dozen states have begun this type of comprehensive planning - bringing together relevant state and local agencies, community leaders, businesses, and stakeholders - through a process to develop Multisector Plans for Aging.[23] Several states have explicitly included disability in their planning efforts, recognizing the significant number of people aging with and into disability and the many common priorities between the communities. The Strategic Plan for Aging Act, introduced by Ranking Member Gillibrand, would help support states to develop and implement Multisector Plans for Aging and Aging with Disabilities, providing momentum to the important work already happening in states and encouraging the important partnerships between aging and disability in this effort to support community living.

The Role of the Administration for Community Living in Supporting Community Living

The Administration for Community Living (ACL) plays a critical role in helping older adults and people with disabilities live and participate in their own communities and age in place. ACL is the only federal agency focused on community living, elevating the issue and ensuring that older adults and disabled people are considered in federal policies across the Department of Health and Human Services (HHS) and the federal government.

ACL funds and implements a wide range of aging and disability programs that support community living, including those under the OAA, Rehabilitation Act, and Developmental Disabilities Act discussed above.[24]ACL has also launched numerous initiatives to address barriers and increase opportunities for community living for both older adults and disabled people, including efforts to support family caregivers,[25] strengthen the direct care workforce,[26] and expand affordable, accessible housing.[27]

ACL has been impacted by HHS' proposed reorganization and reductions in force. ACL has lost almost half of its staff over this calendar year, threatening its ability to fully implement, oversee, and support its aging and disability programs. Consistent with the bipartisan support that ACL has enjoyed, Congress should ensure that ACL is sufficiently resourced to fulfil its statutory mandates, support its programs, and continue its important coordination role across HHS and the federal government.

Thank you for this opportunity to testify about the importance of community living and what it takes to make that a reality for the millions of older adults and people with disabilities in this country. I'm happy to answer your questions.

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[19] https://press.aarp.org/2024-12-10-New-AARP-Report-Majority-Adults-50-plus-Age-Place-Policies-Communities-Catch-Up

[20] https://www.housingwire.com/articles/less-than-5-of-american-homes-are-accessible-for-the-disabled-elderly/

[21] https://aspe.hhs.gov/sites/default/files/documents/9ac2d2a7e8c360b4e75932b96f59a20b/addressing-older-adult-homelessness.pdf

[22] https://endhomelessness.org/blog/paint-by-numbers-older-americans-and-homelessness/

[23] https://multisectorplanforaging.org/

[24] https://acl.gov/programs/aging-and-disability-networks

[25] https://acl.gov/ncsc

[26] https://acl.gov/DCWcenter

[27] https://acl.gov/HousingAndServices

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

PREPARED WITNESS TESTIMONY

Emily Ladau

Chairman Scott, Ranking Member Gillibrand, and distinguished Committee members, I am honored to testify on this auspicious day, as December 3rd is the International Day of Persons with Disabilities.

I am a proud disability advocate, and my mission is to harness the power of storytelling as a tool to expand accessibility and inclusion for all. As a 34-year-old, my story may seem out of place at a hearing about aging in place, but the disability perspective is especially pertinent to today's focus on the impact of community. I want to emphasize that more than 1 in 4 adults in the United States have a disability[1] and of this group, 43.9% are adults aged 65 or older.[2] For those who are not yet disabled, there is a significant likelihood of aging into having a disability. Neither a person's age nor disability status should ever be a barrier to being among loved ones in our homes and communities.

When I was a teenager, my parents and I took a trip to Florida to visit my grandparents for a holiday celebration. At the time, my grandpa was in the midst of an extended hospital stay, but his doctor permitted him to come home for a few hours to join us for a holiday meal. As my family was cooking, I sat with my grandpa while he opened the day's mail. He began to weep over the simple act of being able to do a task in his own home. It's the only time I ever saw him cry. As I look back on this moment, I realize just how strongly it underscores the immense importance of being home-and not just for the holidays.

I was born with my physical disability, so I know well the essential nature of supports and services that empower me to thrive at home and in my community, and how fortunate I am to have had access to them throughout my life. When my mom-who has the same disability as me-was born in 1961, a family member suggested my grandparents place her in an institution. Thirty years later, when I was born, no one made this suggestion to my parents. Instead, following my stay in the neonatal intensive care unit, a public health nurse connected my mom with resources to ensure I'd receive the care I needed.

Because of this, I was able to have regular physical, occupational, and speech therapy starting at just a few months old. By the time I began kindergarten, I was approved for ongoing home and community-based services, or HCBS, thanks to the New York State Care at Home Medicaid Waiver.

Medicaid provided me access not only to vital therapeutic services, but also to home modifications that enabled me to function as independently as possible in my family's home. Medicaid also assisted in the acquisition of durable medical equipment, such as my power wheelchair. As you can see by the fact that I am here today, my wheelchair gives me freedom to be out and about in the community.

Unfortunately, the Medicaid asset limit, which has been a mere $2,000 for over 35 years, became prohibitive to my future career and relationship goals. In my early 30s, I found myself at an inflection point. I wanted to forge ahead in my career and build a life with my partner, but I was trapped in an inflexible system that imposes caps and penalties on people in exchange for access to life-sustaining services, so, with family support, which most people cannot afford, I took a risk and decided not to reapply for Medicaid.

That said, what I am sharing is not a success story about transitioning off Medicaid, as this choice has meant foregoing needed care, such as in-home physical therapy multiple times per week, which I can only access through the Medicaid program. The story here is that HCBS provided by Medicaid were what set me up for success.

This past October, I married the love of my life. My husband and I are now seeking a community to call home near our families in New Jersey. We're searching for

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[1] Centers for Disease Control and Prevention. Disability Impacts All of Us Infographic. Accessed November 26, 2025.https://www.cdc.gov/disability-and-health/articles-documents/disability-impacts-all-of-us-infographic.html.

[2] Centers for Disease Control and Prevention, National Center on Birth Defects and Developmental Disabilities, Division of Human Development and Disability. Disability and Health Data System (DHDS) Data. Acessed November 26, 2025. https://dhds.cdc.gov

somewhere accessible for my physical needs at this stage of our lives as well as for our future needs so we can safely age in place. This search has proven arduous in a housing market where accessible homes are nearly nonexistent.

Our experiences are a stark reminder that the stakes of today's hearing are much higher than heartwarming tales of being home for the holidays. Without access to HCBS and without efforts to prioritize housing and communities that work for everyone, people with disabilities and older adults will all too easily be pushed out of our homes and communities and into institutionalized settings-denied opportunities for everything from education and employment to recreation and socialization.

But we won't be the only ones missing out. Our friends, families, colleagues, and neighbors will miss out on all we can contribute to our communities both socially and economically. This isn't just about making treasured holiday memories with loved ones, although that's a beautiful part of the human experience. It's also about fostering a country where all of us can grow older assured by the notion that we will always have a place to call home.

Thank you.

Questions for the Record

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

QUESTIONS FOR THE RECORD

Alison Barkoff

Senator Raphael Warnock

Question:

More than 47,000 older adults and individuals with disabilities in Georgia rely on Medicaid Home and Community-Based Services (HCBS) for critical personal care assistance, meal delivery, and employment support. On July 4, 2025, President Trump signed the One Big Beautiful Bill Act (OBBB) into law, which cut nearly $1 trillion in Medicaid funding for the next several years.

How will cuts to Medicaid from OBBB affect Georgians' access to HCBS?

Response:

As I discussed in my written testimony, the Congressional Budget Office has estimated that OBBB will lead to over $900 billion in reduced federal Medicaid funding to states over the next 10 years. This is the largest cut to Medicaid in the program's 60 years history.

States must have balanced budgets. To navigate reduced federal Medicaid funding, states will either have to find new funding - from new taxes or taking funding from another program like education - or make cuts to their Medicaid spending. Optional services under Medicaid are at highest risk for cuts. Under Medicaid law, institutional services like nursing home care are mandatory, but HCBS are optional.

History has shown that when states have funding shortfalls in their Medicaid programs, HCBS are among the first to be cut. I, together with researchers from University of California and UMass Boston, examined state behavior during the Great Recession in the 2010s. We found that every single state made cuts to their HCBS programs in response to Medicaid budget shortfalls. The full article is available here, and a table of state-by-state cuts is here.

Cuts to HCBS can happen in different ways. States might eliminate HCBS programs or reduce the number of HCBS "waiver slots," leading to even longer waiting lists. They might cut the hours or types of services available in an HCBS program. Or states may reduce HCBS provider reimbursement rates, which are already so low that they are limiting access to HCBS. KFF has recently published a report on ways that states may manage their HCBS spending in response to OBBB. All of these types of cuts will hurt people with disabilities, older adults and their families; these cuts could force people unnecessarily into institutions and/or force families to take on even more care to fill these gaps.

On a personal level, I am very concerned about cuts to Georgia's HCBS programs. My adult brother with intellectual disabilities is on Georgia's COMP Waiver. His waiver provides him supports to live independently in an apartment with a roommate, with a job coach that supports him at his job at the Georgia Aquarium, and with supports and transportation to participate in community activities. Our parents are in their 80's and would be unable to take on additional care if his waiver supports are cut. Many families across Georgia are in similar situations.

Question:

How will Georgians' access to these services compare to individuals in states like Louisiana that have expanded Medicaid?

Response:

It is difficult to compare the impacts of OBBB on HCBS access between Medicaid-expansion and non-expansion states. All states will face significant cuts to their federal Medicaid funding, regardless of whether they have expanded Medicaid. For non-expansion states like Georgia, the biggest impacts will likely be from new limits on provider taxes, a strategy virtually all states (including Georgia) use to finance their share of Medicaid costs. In addition, Georgia may also be impacted by OBBB's new limits on the use of state directed payments to increase provider rates, limiting state strategies for addressing low reimbursement rates for HCBS providers. The Center for Law and Social Policy has recently released a publication about the im-

pact of Medicaid cuts in non-expansion states, with state-level information. The publication is available here.

As discussed in my previous answer, because all states will face reductions in federal Medicaid funding, optional services like HCBS are at risk of being cut to address those shortfalls. Georgia already has approximately 7,300 people on its waiting list for HCBS waivers. It is facing a direct care workforce crisis due to low wages, and Georgia is still implementing a settlement agreement with the U.S. Department of Justice to expand access to HCBS in its developmental disabilities and mental health systems to address its historical overreliance on institutional care and underinvestment in HCBS. Cuts to HCBS would undermine the efforts in that settlement, would place people at risk of unnecessary institutionalization, and worsen the long HCBS waiting list and workforce challenges.

Question:

The Trump administration cut the workforce at the Administration for Community Living (ACL) by nearly half on April 1, 2025 and proposes to dissolve the agency. Given your prior experience as the Acting Assistant Secretary for Aging and Administrator of the ACL, how will cuts to ACL's workforce affect its important mission of serving older Americans and individuals with disabilities?

Response:

ACL is the only federal agency focused on community living for older adults and people with disabilities. Not only does ACL fund, oversee and support important community living programs like those funded under the Older Americans Act, Developmental Disabilities Act, and more, but it plays a critical role in coordinating across HHS and the federal government to ensure that the unique needs of older adults and disabled people are considered in federal policy.

ACL has been significantly impacted by the reductions in force that have occurred at HHS. Nearly half of the staff is gone, with the termination of the entire teams that work on policy and evaluation, grants and budget, communications and external affairs, as well as all regional staff. The termination of staff has had significant impacts on ACL's ability to get funding out to ACL grantees in a timely manner, forcing grantees like Meals on Wheels providers and Protection and Advocacy Systems to reduce services due to delays in receiving funding following the passage of the Continuing Resolutions in March 2025 and again this November 2025. The elimination of the policy team has meant that there are no staff remaining to continue ACL's important work with other HHS agencies on policies that impact people with disabilities and older adults, particularly policies related to HCBS issued and implemented by the Centers for Medicare and Medicaid Services (CMS), and the elimination of all regional staff has meant that there are no staff in the field to provide technical assistance to grantees and to coordinate responses in emergencies like natural disasters.

Not only has ACL been impacted by termination of staff, but HHS has proposed to eliminate ACL as its own agency and move it as a sub-agency into the Administration for Children and Families. This will further hinder ACL's ability to fulfill its role coordinating aging and disability policy across HHS and with other federal agencies.

In May, I testified at a hearing led by Senators Welch and Baldwin entitled ″Trump's Destruction of HHS: Mass Firings, Reorganizations, and the Human Harm Caused.″ In my testimony, I discussed the devastating harms caused by the termination of staff, reorganization, and cuts proposed in the President's Budget. Senator Welch's press release is here, with a link to a video of my testimony. I also am attaching a copy of my written testimony. In addition, I recently published an article in the Public Policy and Aging Report, a peer-reviewed publication of the Gerontological Society of America, entitled ″How the reorganization, staff terminations, and proposed program cuts at the U.S. Department of Health and Human Services will impact older adults and disabled people,″ with a focus on the impacts at ACL. I also am attaching a copy of that article here.

Alison Barkoff - Attachment for "Questions for the Record"

Attachment 1: Alison Barkoff written testimony from May 21, 2025 Senate Democratic Spotlight Hearing, "Trump's Destruction of HHS: Mass Firings, Reorganization, and the Human Harm Caused."

Senate Democratic Spotlight Hearing
"Trump's Destruction of HHS: Mass Firing, Reorganization, and the Human Harm Caused"

Testimony as prepared by Alison Barkoff, J.D.
Hirsh Health Law and Policy Associate Professor, George Washington University and Former Acting Assistant Secretary for Aging and Administrator of the Administration for Community Living, Department of Health and Human Services

May 21, 2025

Good afternoon Senator Welch, Senator Baldwin and other Senators. Thank you for inviting me to today's hearing.

I am Alison Barkoff. I served in the role of Assistant Secretary for Aging and Administrator of the Administration for Community Living or ACL under President Biden. I am now a health law and policy professor at George Washington University.

Thank you for the opportunity to share the devastating impact that the Trump Administration's dismantling of ACL is having on the tens of millions of older adults, people with disabilities and caregivers who rely on its programs to live in their own homes and communities rather than in nursing homes and other institutions.

ACL provides critical, life-sustaining supports to older adults, disabled people and their caregivers. These programs include, among many others:

- Meals on wheels, delivering over 260 million meals and connection each year to homebound older adults;
- Support to more than 1.5 million family caregivers annually;
- Help transitioning over a quarter million people to their own homes from a hospital or nursing home stay; and
- Assistance to over 50,000 disabled people and their families in accessing healthcare, assistive technology and other services.

ACL's programs are cost-effective. For example, one year of home delivered meals costs less than one day in the hospital. They also save hundreds of millions of dollars annually to other programs like Medicare and Medicaid by preventing unnecessary emergency room, hospital and nursing home admissions.

While ACL is one of the Department's smaller agencies, its programs have a huge reach. One in 5 older adults – 11 million Americans – rely on ACL's aging programs. One in 4 Americans – 70 million people – have a disability, with nearly a quarter benefitting from ACL's disability programs. The need for ACL and its programs is increasing exponentially, with over 11,000 people turning 60 each day and a growing population of disabled people living longer.

That's why it is astounding that the Trump Administration is dismantling ACL and proposing to eliminate dozens of its essential programs. ACL is being eliminated in the HHS reorganization and its "critical" programs scattered among three other HHS agencies. The very efficiencies that led to the creation of ACL – coordination of programs at the federal, state and local levels – will be gone.

The Trump Administration has fired nearly half of ACL's staff, including its entire budget, grants, policy, evaluation and regional staff. That is making it nearly impossible for the remaining staff to timely fund and implement ACL's programs.

The White House, in the leaked April OMB passback, is proposing to completely eliminate nearly 20 major aging and disability programs. This includes all of the programs that protect older adults and disabled people from abuse and neglect, despite promises to protect "vulnerable" people. It includes most of the evidence-based healthy aging programs, despite claiming the HHS reorganization is to focus on disease prevention. And it includes eliminating all of the programs that support people with developmental disabilities, including autism – programs under a law championed by Secretary's Kennedy's father and uncle and despite Secretary Kennedy saying autism is a priority.

Due to funding delays and uncertainty about the future of programs, people are losing access to critical services they rely upon daily to stay in their own homes and communities. The aging and disability networks are small and underfunded. They can only endure funding delays for short periods – many for as little as two weeks – before services are impacted.

That is exactly what happened this spring as HHS delayed disbursing funds passed by Congress in the March Continuing Resolution. Some aging providers began declining new referrals and had to put people on waiting lists, including for meals. Some protection and advocacy agencies had to stop intake and limit monitoring for abuse and neglect. Most agencies have had to divert resources away from providing services to emergency contingency planning.

Only because of strong stakeholder advocacy, media, and oversight from you, HHS temporary brought back staff and finally disbursed formula grant funding from the CR over the last several days. Other grants funded by Congress in the CR are still delayed, and staff will be gone by early June, making it unlikely that this appropriated funding will be disbursed.

The harms from dismantling ACL and eliminating critical aging and disability programs is compounded by the efforts of Republicans in Congress to decimate Medicaid with the largest cut in the program's history, threating additional community services that older adults and disabled people rely on.

All of this together will roll back decades of progress. Older adults will be forced into understaffed nursing homes rather than being able to age in place. Disabled people will be shuttered away from society, taking us back to the days of Willowbrook.

ACL's aging and disability programs wraparound and serve as the glue and coordination that increase the efficiency of Medicaid, Medicare, Social Security and other large federal programs. Simply put, community living is not possible without ACL and its critical programs.

Thank you for all of your efforts to stop this devastation and to support older adults and disabled people. I look forward to your questions.

Alison Barkoff - Attachment for "Questions for the Record"

Attachment 2: Alison Barkoff. "How the Reorganization, Staff Terminations and Proposed Program Cuts at the U.S. Department of Health and Human Services Will Impact Older Adults and Disabled People." Public Policy and Aging Report (Fall 2025).

Public Policy & Aging Report, 2025, **00(00)**,1–4
https://doi.org/10.1093/ppar/praf020
Policy Analysis Article

GSA GERONTOLOGICAL SOCIETY OF AMERICA® OXFORD

How the reorganization, staff terminations, and proposed program cuts at the U.S. Department of Health and Human Services will impact older adults and disabled people

Alison Barkoff, JD*

Department of Health Policy and Management, Milken Institute School of Public Health, The George Washington University, Washington, District of Columbia, United States

*Address correspondence to: Alison Barkoff, JD. E-mail: Alison.Barkoff@gwu.edu

Decision Editor: Michael J. Lepore, PhD, FGSA

Keywords: Aging, Disability, Community living, Older Americans Act, Research

The first six months of the Trump Administration has brought significant changes to federal agencies, from major reorganizations and termination of staff to rescissions of grants and elimination of programs. The U.S. Department of Health and Human Services (HHS) has been among the most impacted, with a reorganization that eliminates over a dozen agencies and 20,000 staff (Assistant Secretary for Public Affairs [ASPA], 2025; Assistant Secretary for Public Affairs Press Office, 2025). It has been a constantly evolving landscape, with legal challenges, strong stakeholder advocacy, and reassessment of needs leading to ongoing changes in HHS' plans. This article, which is being written amid this uncertainty, focuses on how these changes may impact older adults and people with disabilities, particularly the elimination of the Administration for Community Living (ACL) as a separate agency focused on aging and disability programs and policy.

The first six months of the Trump Administration has brought significant changes to federal agencies, from major reorganizations and termination of staff to rescissions of grants and elimination of programs.

Administration for Community Living

Background on the ACL

The ACL was created in 2012 as an independent agency within the HHS, bringing together programs from across the HHS (and later other departments) that support older adults and people with disabilities (ACL, 2025d). Its creation advanced program efficiency and coordination at the federal, state, and local levels. ACL's mission is to ensure that all people, regardless of age or disability, have the opportunity to live and participate in their communities (ACL, 2024). ACL's administrator, who also serves as the Assistant Secretary for Aging, is the advisor to HHS' secretary on aging and disability policy and a member of the secretary's leadership team (ACL, 2025a).

The ACL funds and implements a range of aging programs, the majority of which are authorized by the Older Americans Act (OAA). These include congregate and home-delivered meals, in-home supports, senior centers, transportation, family caregiver supports, and the Long-Term Care Ombudsman program (Colello & Napili, 2024). OAA programs are implemented through the aging services network, made up of State Units on Aging, Area Agencies on Aging, and other community-based organizations (ACL, 2025c).

In addition, the ACL funds and implements a range of disability programs to support disabled people of all ages, including older adults, primarily funded through the Developmental Disabilities and Rehabilitation Acts (ACL, 2025e). It also oversees programs to assist Medicare beneficiaries in navigating health care benefits, including the State Health Insurance Program (ACL, 2025b). Finally, the ACL funds discretionary grants focused on issues important to older adults and people with disabilities, such as family caregiving and affordable housing.

HHS reorganization, reduction in force and budget

In March 2025, the HHS announced a major reorganization, consolidating its 28 operating divisions into 15 and terminating 10,000 employees (in addition to the 10,000 staff who had recently been terminated or taken early retirement). The ACL would be eliminated and "[c]ritical programs that support older adults and people with disabilities will be integrated into other HHS agencies, including the Administration for Children and Families (ACF), [the Assistant Secretary for Planning and Evaluation] (ASPE), and the Centers for Medicare and Medicaid Services (CMS)" (Assistant Secretary for Public Affairs Press Office, 2025). Eliminating the ACL as a separate agency would mean the loss of someone at the HHS leadership table to advocate for older adults and people with disabilities in all HHS policies, and splitting ACL's programs across three agencies would undermine the program coordination that was a driver for the ACL's creation.

Received: June 18 2025; Accepted: September 4 2025
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Several days later, the HHS notified thousands of staff across the Department that they had been terminated as part of a reduction in force (RIF). More than 40 percent of ACL's staff was fired, including its entire budget and grants teams, policy and evaluation teams, and regional staff (Cody, 2025). The elimination of these roles means there will no longer be regional staff to provide on-the-ground technical assistance or coordination during emergencies or policy staff to provide input about the needs of older adults and people with disabilities in policies developed across the Department. The RIFs also had immediate impacts; with the termination of the entire budget and grants teams, the ACL had no staff to distribute funding that had been passed by Congress weeks earlier to fund the remainder of the fiscal year. By late April, the funding delays led to reductions in critical services, waiting lists, and the necessity to decline new clients, including for home-delivered meals for older adults and legal assistance for people with disabilities of all ages (Abelson, 2025).

Following the announcement, the HHS provided no information about which programs would continue or be eliminated and to which agencies continuing programs would be reassigned, despite requests from stakeholders and Congress (Gillibrand et al., 2025). Then in mid-April, a White House document with proposed funding for HHS' Fiscal Year 2026 budget was leaked to the public, shedding light on the plans for the ACL (Garcia, 2025). It confirmed the ACL's elimination and identified the programs that would move to each of the three other agencies, including splitting OAA programs between two. The document also proposed to eliminate 17 programs that collectively serve millions of older adults and people with disabilities, including programs protecting their safety like the Long-Term Care Ombudsman, Adult Protective Services, and Protection and Advocacy programs; programs that support caregivers like the Lifespan Respite Care and Developmental Disabilities Act programs; and programs that advance the health of older adults like the Chronic Disease Self-Management Education and Falls Prevention programs (Faust, 2025a; Faust, 2025b).

Aging and disability organizations advocated to prevent the elimination of programs and urge the HHS to keep ACL's programs together, putting out statements, activating their grassroots, and engaging with members of Congress (Blancato & Hollander, 2025; USAging, 2025b). They also continued to push the HHS to release the funding appropriated by Congress, highlighting the growing impact caused by funding delays (USAging, 2025a). Additionally, Democratic Senators held a hearing on the impacts of the HHS reorganization (Peter Welch U.S. Senator for Vermont, 2025).

This advocacy made a difference. In early May, the HHS announced it would disburse the appropriated funding to ACL's networks (U.S. Department of Health and Human Services Press Office, 2025). In late May, President Trump submitted to Congress the Fiscal Year 2026 budget documents for each department. His final budget reversed course from the earlier proposal in significant ways. The continuing aging and disability programs will now move together to a renamed Administration for Children, Families and Communities instead of being split up. It also proposes to continue funding many of the programs that had been eliminated in the leaked White House document, including the Long-Term Care Ombudsman program, Lifespan Respite Care program, State Health Insurance Program, and Protection and Advocacy program for people with developmental disabilities (U.S. Department of Health and Human Services, 2025).

Unfortunately, the President's budget still proposes eliminating a number of programs, including the Chronic Disease Self-Management Education program and several programs that support people with paralysis, limb loss, and developmental disabilities. It also proposes reduced funding for several aging programs, including the Falls Prevention program, Native Elders program, and Alzheimer's disease programs, as well as a small funding increase for elder justice programs. Finally, it reduces ACL's staff by nearly 50 percent, incorporating in the RIFs (ACFC, 2025).

Litigation related to HHS' reorganization and RIFs

Litigation has been brought challenging HHS' reorganization and RIFs. In a lawsuit led by unions representing federal employees, the court granted a preliminary injunction pausing the reorganization and RIFs at several departments, including all of the HHS. In early July, the U.S. Supreme Court lifted the injunction, allowing the HHS to move forward with terminations while the litigation continues. On the evening of July 14, many HHS staff who had previously received RIF notices—including nearly one-half of ACL's staff—were notified they were permanently terminated as of close of business (Heckman, 2025). While not impacting the ACL, staff terminations at a handful of HHS agencies—specifically a couple of units in the Centers for Disease Control and Prevention (CDC), Food and Drug Administration, and Assistant Secretary for Planning and Evaluation—remain paused due to an injunction issued in a separate lawsuit brought by nearly twenty states, which is on appeal at the time of this writing (Marsh et al., 2025).

Aging and disability programs in other HHS agencies

Aging and disability programs in other HHS agencies—particularly the CDC and National Institutes of Health (NIH)—have also been impacted. The HHS announced, as part of its reorganization, the refocusing of the CDC "on returning to its core mission of preparing for and responding to epidemics and outbreaks" and the termination of 2,400 CDC staff (ASPA, 2025). All staff at the National Center for Chronic Disease Prevention and Health Promotion's Healthy Aging Program were terminated, although their separation is currently paused due to the state lawsuit. These staff oversaw funding for state and local public health agencies for initiatives on Alzheimer's disease, caregiving, and aging research (Centers for Disease Control and Prevention, n.d.). The President's budget proposes to permanently eliminate the entire center other than some Alzheimer's disease programs that will move to the new Administration for a Healthy America at reduced funding levels (Administration for a Healthy America, 2025). The CDC's disability programs have also been impacted, particularly by the termination of nearly 40 percent of the staff in its National Center on Birth Defects and Developmental Disabilities and elimination of the Center's Disability and Health Promotion Branch (all currently paused due to the state lawsuit), as well as the termination of the CDC's Chief Disability Officer (Clark, 2025).

NIH's National Institute on Aging (NIA) has also been impacted. The HHS reorganization called for a consolidation of NIH institutes and termination of 1,200 NIH employees (ASPA, 2025). While the NIA will remain a separate institute, some NIA staff appear to be included in the NIH RIFs. The President's budget proposes to cut $1.8 billion from NIA—over 40 percent of its funding—and reduce its staff by nearly 25 percent (National

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Institutes of Health Office of Budget, 2025). In addition, the NIH has terminated more than 2,000 grants deemed inconsistent with the Trump Administration's new priorities, estimated to total over $3.8 billion (Nietzel, 2025). Terminated grants impacting older adults and disabled people included grants related to Alzheimer's disease, COVID-19, and HIV (Jauregui-Volpe, 2025). The NIH's grant terminations are being challenged in several lawsuits, with one court recently granting a preliminary injunction to pause them (Wiessner & Raymond, 2025).

Finally, HHS programs disproportionately used by older adults and disabled people have been impacted. For example, many of them rely on the Low Income Home Energy Assistance Program (LIHEAP) for help with heating, cooling, and weatherizing their homes. The HHS terminated the entire LIHEAP team, leaving no staff to implement the program (National Consumer Law Center, 2025), and the President's budget proposes to eliminate LIHEAP (U.S. Department of Health and Human Services, 2025). Similarly, HIV and AIDS are disabilities that disproportionately impact older adults (NIH, 2024). The HHS has already cut numerous HIV and AIDS programs, and the President's budget proposes to eliminate many HIV prevention programs (Choi, 2025; HIV+Hepatitis Policy Institute, 2025).

Conclusion

The future of many HHS aging and disability programs is uncertain (Gleckman, 2025). The elimination of the ACL as an independent agency and the termination of nearly one-half its staff will have both immediate and long-term impacts. Older adults and people with disabilities have lost their voice at the HHS leadership table, limiting the ability to bring an aging and disability lens to policies departmentwide. The termination of ACL staff will have lasting impacts, including loss of expertise and challenges in distributing and monitoring funding, providing on-the-ground technical assistance to grantees, and shaping policies across the Department.

The elimination of the ACL as an independent agency and the termination of nearly one-half its staff will have both immediate and long-term impacts. Older adults and people with disabilities have lost their voice at the HHS leadership table, limiting the ability to bring an aging and disability lens to policies departmentwide. The termination of ACL staff will have lasting impacts, including loss of expertise and challenges in distributing and monitoring funding, providing on-the-ground technical assistance to grantees, and shaping policies across the Department.

At the same time, it is positive that ACL's continuing aging and disability programs will remain together, allowing the synergies and efficiencies across programs to continue. While Congress ultimately makes funding decisions, the fact that the President's budget reversed course and proposes to fund a number of aging and disability programs that were previously targeted for elimination makes it more likely that these critical programs will continue. In short, advocacy has blunted some of the most devastating impacts from the HHS reorganization vis-à-vis the ACL.

Looking across the HHS, older adults and people with disabilities have already been negatively impacted by the reorganization and will be further harmed if additional proposed cuts come to fruition. Termination of grants and reductions in funding for aging research, research on conditions common in older adults and disabled people (like Alzheimer's Disease and HIV), and programs that disproportionately assist these populations (like LIHEAP) have already led to short-term harm and will have long-lasting impacts. These impacts will be compounded by the significant cuts to other programs critical to older adults and disabled people, like Medicaid and the Supplemental Nutrition Assistance Program, in the recently passed reconciliation bill (Schubel, et al., 2025; Barkoff & Ku, 2025). Continued strong advocacy by aging and disability stakeholders will be critical to preventing further harm and to hopefully succeeding in eventually reversing some of the harmful impacts to date.

Funding

None declared.

Conflict of interest

I have no known conflict of interest to disclose.

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U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

QUESTIONS FOR THE RECORD

Emily Ladau

Senator Raphael Warnock

Question:

More than one in four adults live with a disability in the United States. Employees with disabilities at the Department of Health and Human Services (HHS), including Centers for Disease Control and Prevention (CDC) workers in Georgia, are facing unjust and haphazard policies that rescind reasonable accommodations (RA) and create obstacles for reapplication.

As a disability rights advocate, why is teleworking an important part of providing RAs?

How can Congress protect the rights of employees with disabilities against unjust accommodation policies?

Response:

Thank you, Senator Warnock, for inquiring about these essential topics. First, I'd like to address the value of teleworking as a reasonable accommodation. I've been teleworking in some capacity since 2013, well before it became a more standard practice because of the COVID-19 pandemic. As a physically disabled woman who did not yet have my driver's license after I graduated college-because I needed more intensive adapted lessons and an adapted vehicle-I worked remotely starting with the first full-time job I had. This reasonable accommodation proved to be essential as I began to build a career in disability advocacy and communications, allowing me to work from an environment that was fully accessible for me (my home) so I could deliver my best work.

In the face of the devastation of the COVID-19 pandemic, it was heartening to see how employers and employees alike benefitted from implementing telework policies. It opened up flexible and safe work opportunities, creating pathways to employment for disabled people who could not previously sustain jobs for any number of reasons, such as being immunocompromised or having a chronic condition. As employers now continue to try to shift back to in-person work, I urge them to keep in mind that telework is not a barrier, but a boon for workplaces.

Regarding accommodation policies more broadly, I urge Congress to recognize that reasonable accommodations are not "special treatment" and to better understand the purpose that they serve in the workplace. While some policymakers may believe that reasonable accommodations are simply part of "diversity, equity, and inclusion" initiatives that they are insistent upon shutting down, the reality is that disability does not choose political sides. Anyone can acquire a disability at any time due to an accident or onset of an illness, regardless of their views. As such, all employees should always have access to reasonable accommodations. Beyond that, reasonable accommodations are tools that empower employees to fulfill their duties, maximizing workplace productivity and overall success. There should not be a culture of fear around requesting reasonable accommodations, nor should the request process be a cumbersome waste of time, as this is only to the detriment of progress in the sphere.

Statements for the Record

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Alabama

Barbara Del Rio, Birmingham, Alabama

Dear Members of the Special Committee on Aging,

My son, Josh, has Duchenne Muscular Dystrophy, he is 34 now. Our family have been following the research of this awful progressive disease for many years and Josh has benefited from improved treatments due to the research but nothing has stopped the progression of DMD and the devastating weakness it has caused.
Josh thinks often about his future, he still has hope. Please don't cut HCBS funds. If you do you'll end Josh's hope and others that suffer from DMD of a future. Josh has been a warrior since he was a little boy… fighting through his anxiety as his body grows weaker and his peers grow stronger.
He is wheelchair bound and needs assistance with all personal and medical care but he fights on! You have no idea of the courage he has shown. I'm calling on you to match his courage and support the Medicaid medical and HCBS programs that have allowed him to benefit from new treatments, go to college and be employed.

Melanie Felker, Hunsville, Alabama

Dear Members of the Special Committee on Aging,

Community living matters to me because I live with brittle Type 1 Diabetes and Progressive Multiple Sclerosis. Both have also allowed other conditions to attack my body (with hardly any ability to fight things off): chronic fatigue, chronic anxiety, depression, peripheral and autonomic neuropathy, radial palsy in my hand, asthma, chronic obstructive pulmonary disease, OCD, and more. That is 8 of my 23 chronic conditions that I have had since born in 1964.

I go to about 6 doctors every 3 months for checkups. And there have been times when me MS has been so active that I could barely walk or get out of bed, not make food for myself, not get to the Dr. For 25 years or so my ability to fight off colds, illnesses, etc has been very difficult due to very, very low White Blood Cell counts. But in the past 4 years I was put on a new medication for MS which doesn't wreck my blood count.

The home health services that Part A on my card provided is amazing. I fell in a hallway at my house in 20176 fracturing part of my left leg and breaking another bone in half. After spending a week in the hospital, and 6 weeks healing in a nursing center. When I got home, for 2 month had my rehab exercises in my den. Part A took care of it all. It provided nurses and physical therapists to come help me reuse my legs and ankles/feet. They also assisted in getting hand bars to put in rooms/halls.

In 20221/22 I moved to a retirement home. In January 2023 I had problems of falling one night, due to an MS/diabetic condition.
My head hit a bookshelf hit my head and crack on my skull. And MS flared up more because of the stress. Again, Part A provided me with nurses and therapists to assist me in balance, walking, standing, eating, bathing. And they assisted with grab bars around my apartment. They stayed with me for about 3 months, until I was able to walk and stand without trouble.

Home and community based services for keeping health working right is a wonderful thing for us to have. For all cities and towns to be able to take part in when needed. Otherwise, people would be spending lots of money, which they may not have, on staying in a nursing home, the hospital, etc for help, or not getting assistance.

Frances Jones, Mobile, Alabama

Dear Members of the Special Committee on Aging,

Community living matters to me because as an 84 year old Senior I need special services to accommodate the physical changes of aging; self-grooming; walking with a cane & other assist devises; difficulty to access transportation (driving is a chore); shopping for groceries is tiresome & costly; feeling safe & secure at night, etc.

Kenneth Thrash, Wetumpka, Alabama

Dear Members of the Special Committee on Aging,

Community living matters to me because everyone deserves a equal chance

---

Candace Rose, Birmingham, Alabama

Dear Members of the Special Committee on Aging,

Community living matters to me because I deserve it. Just like anyone else.

Kim Spangler, Birmingham, Alabama

Dear Members of the Special Committee on Aging,

Community living matters to us because there is no better way to help my child with a disability learn the value of contributing to society while he experiences the freedom of choice and responsibility of independence. My 27 yo son, Colby has overcome so many challenges to get to

where he is now that his appreciation for community is solid and rooted in determination. Colby has CP and lives with 2 other roommates who also have disabilities. They live an hour away from us in a rental home near his work. He works pt and commutes using his electric scooter. He stops to chat with neighbors as he comes and goes and enjoys church activities with his same aged non disabled peers. While he graduated from a post secondary program for young adults with intellectual or developmental disabilities, he decided to continue his learning and attended a graduate training program through an accredited Bible college. Colby grew to love the campus and town of Tuscaloosa so much that the thought of moving back home to live with mom & dad was less appealing than he'd have ever imagined. He worked hard for years to save money displaying his strong work ethic and capacity for obtaining personal growth. Colby will tell you, he's living his best life alongside family and friends. His community has embraced his love of nature and his passion to learn more about life. He participates in the local BEST BUDDIES program, Unified Olympics and volunteers in local outreach ministries with his church. Colby & his roommates are accomplishing great things and living well in the community they chose. You can see more about Colby's contributions to the community here: https://youtu.be/00ahyKABIAw?si=3m9uniUF0HtG_1Hm The Colby Act was passed in August of 2023 and has led many to a place of much needed support from within their own communities. Colby enjoys telling his story and pointing people toward Community Inclusion.

Statement of
KENDRA DAVENPORT
President and CEO of Easterseals

for THE UNITED STATES SENATE SPECIAL COMMITTEE ON AGING

Concerning "Protecting Older Americans: Leveling the Playing Field for Older Workers"

December 10, 2025

Chairman Scott, Ranking Member Gillibrand, and Members of the Committee:

Thank you for the opportunity to submit testimony for the record. I am Kendra Davenport, President and CEO of Easterseals. Our organization provides services and support to millions of individuals and families each year through a national network of Affiliates that spans forty-eight states and the District of Columbia. We serve older adults, people with disabilities, veterans, and caregivers to better ensure they are able to live full and independent lives.

For more than two decades, Easterseals has been a national grantee for the Senior Community Service Employment Program (SCSEP), the only federal workforce program specifically designed to serve unemployed, low-income adults aged fifty-five and older. Through SCSEP, older adults gain access to paid, part-time community service assignments that help them build job skills, increase income, and prepare for permanent employment. The program provides over 40 million community service hours to public and non-profit agencies, allowing them to enhance and provide needed services. Participants work in schools, senior centers, food pantries, and other local agencies, contributing meaningful service while building the experience and confidence they need to reenter the workforce.

Easterseals currently operates SCSEP in 10 states and 150 counties. Since 2003, our participants have contributed more than 10 million hours of community service nationwide. Most participants earn around $1,200 per month through this program. For many, these wages are essential, helping cover rent, utilities, medications, and groceries. This income not only meets daily needs, but also keeps participants engaged and connected to their communities, giving them a sense of purpose and helping avert loneliness so many isolated seniors experience.

Approximately 65% of SCSEP participants receive some form of public assistance, such as Medicaid or SNAP. Many of these same individuals are now subject to new Medicaid work requirements. It is deeply counterproductive to deny them access to the one program designed to help them meet those requirements.

Unfortunately, this essential program is in crisis. Congress appropriated $405 million in funding for SCSEP this fiscal year, but the Department of Labor only recently released the funds. As a result, Easterseals and many other national SCSEP grantees were forced to furlough participants and suspend job placements. These disruptions caused economic hardship for thousands of older adults. Grantees are expected to spend down funds for the entire year in just seven months, with no guidance from the Department of Labor on whether the program will be renewed. For many older adults who rely on SCSEP as their primary source of income, the lack of definitive appropriations leaves them without a stable path back to work or financial security.

To be clear, grantees like Easterseals successfully competed for and were awarded SCSEP funds through a rigorous process. By releasing program funds, the Department of Labor would honor its commitments to our organizations and the communities we serve.

We respectfully ask this Committee to urge the Department of Labor to notify grantees and release SCSEP funds in a timely manner in the future. Without action, the impact of this delay will continue to grow. Older adults who want to work, and who rely on this program to help them do so, are being left behind at a time when our workforce needs them most.

This delay also comes at a time when the Department of Labor is taking broader actions that threaten the progress of disability and older adult employment across the country. These include proposals to eliminate long-standing affirmative hiring benchmarks and roll back equal opportunity protections.

Thank you for the opportunity to share Easterseals' experience with this important program. We stand ready to support the Committee's continued efforts to ensure that older adults can age with purpose, with dignity, and with access to opportunity.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Alaska

Heather Ogle, Sterling, Alaska

Dear Members of the Special Committee on Aging,

Community living matters to me because everyone needs support in life, at one point or another. For some, it's help thriving, for others it can mean literal survival.

Since losing our Dad in late 2022, life has become increasingly difficult. We've realized that our Mom is declining cognitively. She relies on monthly survivor's social security checks, but it doesn't cover her medical bills and medications. We've just learned that the 340B care card program she uses to cover the outrageous cost of her meds are no longer available starting January 1st 2026.

In July of 2024, after several months of unresolved health issues, my 12 year old son was diagnosed with Crohn's disease. Life has not been fun for him. He needs very expensive infusions every 6 weeks to manage symptoms and keep the inflammation from progressing. It's been extremely challenging to balance work and time with my family. I've been trying to navigate resources for paid family care givers, but it's looking bleak. There's so much more to our story, including my own health issues, being BRCA1GENE positive.

Our lives are greatly impacted by these programs. They are vitally important to me and my family.

Thank you for your time.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Arizona

Aria Faamasino, Mesa, Arizona

Dear Members of the Special Committee on Aging,

Community living matters to me because it trancends the prosperity of humanity when everyone works in unification.

Shannon Sharifi, Tempe, Arizona

Dear Members of the Special Committee on Aging,

Community living matters to me because,
People with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. Programs like Medicaid home and community-based services (HCBS) help make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.

Susan Singler, Sahuarita, Arizona

Dear Members of the Special Committee on Aging,

Community living matters to me because my son can live with me and not in a nursing home. He is able to live as independently as possible. He can enjoy and participate in community activities in our neighborhood. It's inclusion in the best sense of the word. He sings and can showcase his talent in our Christmas song along and Variety Show. Our friends and neighbors expect him to attend and sing Karaoke at the monthly events. He has made friends and is a valued member of our community where he enjoys monthly dances, the swimming pool, and the fitness room. His caregivers help him attend many of these activities and events. His neighbors speak to him when they see him walking in the neighborhood, and he's invited to their homes. Oh yes, Nathan is 43 years old; he is blind with intellectual and developmental disabilities. He also has Cerebral Palsy that has affected his mobility requiring him to use a walker and often, a wheelchair. And he is kind, funny and so very talented. He has performed The National Anthem for our local Special Olympics and other charitable organizations for individuals with disabilities. Ask yourselves this, would he be contributing to his community if he lived in a nursing home? Home and Community based services allow our family members with disabilities to thrive, not just survive, and these supports help family caregivers to work, and have much needed respite to recharge. And an added benefit? Home and community based services costs less than a nursing home placement.

Deidre Gotjen, Phoenix, Arizona

Dear Members of the Special Committee on Aging,

Community living matters to me because I care about people.

Joyce Carter, Mesa, Arizona

Dear Members of the Special Committee on Aging,

Community living matters to me because they deserve the right to live their lives

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Darlene Lundergan, Tucson, Arizona

Dear Members of the Special Committee on Aging,

Community living matters to me because my adult son on life support would not be with us today if it wasn't for him living at home. He is IDD, Blind, Hard of hearing, respiratory decency, CP, Oxygen, Tracheostomy, Gtube, and much more. He lived at a hospital, TMC, for one year. He was the first person home on a Ventilator in Tucson. The Doctors sent him home to die. They said 90 days at best and here he is 38 years later. He never would have survived an institution plus we don't have any for Ventilated people. So..Home and Community Living keeps people happy and alive.

Jo-Anne Gutsch, Surprise, Arizona

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a 33 year old son who is autistic and non verbal. It's hard for him to have friends because of this. He goes to a day program now and he has made so much progress. He never really wanted to participate in group activities. Now he does, he gets more involved than he ever did before. He enjoys learning new things/skills. His behavior has improved, he's learning how to deal with other people and how to handle certain situations. He loves to go on outings to the movies, bowling and the park.
When they were closed during Covid he had a very hard time keeping himself busy. There was only so much we could do without being able to go anywhere.
Without these programs he would be miserable. He looks forward to going and seeing his friends.
It's wonderful as a parent to see him smiling, learning and just enjoying life.

Jennifer Becker, Tucson, Arizona

Dear Members of the Special Committee on Aging,

Community living matters to me because humans are of diversity in appearance and abilities, but not worth. Service goes two ways, and we are all of differing abilities and assets.

Monti Worsham, Phoenix, Arizona

Dear Members of the Special Committee on Aging,

My experience with community and home based services - and the System in general - has not been very positive. In fact, I'd go so far as to say they are the cause of much distress, which only seems to be getting worse with time. Frankly, what community and home based services?

The services I have received, have primarily proved to be wrought in bureaucratic processes and delays. Which, have caused frustration and exacerbation of symptoms. The System has been harmful when it's supposed to be helpful. Even the clubhouse model of peer support has become a much less helpful environment than it used to be. The last time I reached out, nobody responded

I was designated SMI (Serious Mental Illness) after being assaulted and sustaining a head injury. When in fact this is a mis- categorization. As, I have been diagnosed with autism and a history of trauma. These are not inherently severe psychiatric disorders. As a result, I was subjected to forced, unnecessary and contraindicated court petitioning, psychiatric evaluation, treatments and medications that have caused much harm. This could have all been avoided, had I been given due process, if legal procedural protections has been afforded, if I'd received notification of my rights, and if someone would just listen to me.

With the autism, it is best to allow me time to process things instead of just putting me on the spot to develop ISP's, etc. Plus I probably shouldn't even be in the mental health system. I'd probably be a better candidate for the DDD system, but I was discouraged from applying for help from DDD due to funding limitations

I've been seeking community based services for autism and complex trauma for years now to no avail. Seriously. It's been since 2019 or before, that I've been asking for trauma therapy. I received one referral but the counselor was a student and not a good fit. Our sessions lasted about 6 months and she pressured me into therapies that are generally not effective for people with autism. She expressed being unwilling to even hear that my apartment had roaches - how would she be able to hear and help with the really bad traumatic experiences I was in need of getting off my chest?

I've asked for accommodation regarding help with understanding the large amount of consent forms required by the Community based healthcare System. My request was denied. So, currently I am in limbo with no help. This has been going on for months. I've switched clinics in an attempt to find a provider of community based services that will provide appropriate services. I'm still searching and waiting. And in the interim I am without support or the correct treatments and services for the conditions I actually have and not for the misdiagnosis I've been labeled with.

Because of being forceably detained against my will and assaulted in psychiatric hospitals and in the community, I have a difficult being in the community. I have yet to find a community based treatment team or system that isn't causing more harm than helping.

You asked

I am struggling to find something good about the System. I was for a while getting some help at a peer run organization. However, the last few times I attended - I actually felt worse by the end of the day than when it started.

I enrolled in Voc Rehab only to be chastised and disrespected by one of their counselors.

I struggle daily with symptoms, and lack of appropriate services and support. My health is not good and yet I get up each day and try to make the best of it. I feel beaten up, exhausted and discouraged by the end of most days. The System that's supposed to be helping people to heal is actually causing much harm and delaying and interfering with healing in the process

---

Kristina Mitschke, Marana, Arizona

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter works in a dementia center and tells me every day that she would never put me in a place like that, but I have lived with a failed back fusion for over 25 years already. There is no hope of it ever getting better, but sadly I will end up in a wheelchair needing help instead. We will need the help of the state, because I am on Medicare now. I don’t see that changing anytime in the future.

Patricia Vance, Tucson, Arizona

Dear Members of the Special Committee on Aging,

Community living matters to me because some people need a little supervision to help them make it through this life.

Ché Leone, Sedona, Arizona

Dear Members of the Special Committee on Aging,

Community living matters to me because I am the mother and guardian of young woman now 28 years old, who was born with a rare chromosome anomaly. This is anomaly greatly affected her cognitive, emotional and psychological development to the point of making her unsafe and unsteady in the world. I have advocated for her to receive services in the community and in her home to help her live an independent and safe life. She contributes back to the community by volunteering, with support from her staff. She is happy and is at peace within herself because she has the support from home and community based services. She would be either hospitalized or dead if these services were not in place I am grateful that I was able to advocate for her to receive the support she absolutely needs.

Juanita Gonzalez, Cottonwood, Arizona

Dear Members of the Special Committee on Aging,

Community living matters to me because I am an advocate for people with special needs. The need all the services they can get to be able to live fulfilling lives. They cant afford two loose anymore services as they have already lost s many in the past. If anyone deserve this funding it is our special needs community.

Christine Scianna, Surprise, Arizona

Dear Members of the Special Committee on Aging,

Community living matters to me because I saw what can happen in a group home. My daughter was unfairly targeted by DCS, because she had so many hospitalizations when she was a teenager. ABC News shared our story on both November 21st 2024 and in October, 2025, as a part of an ongoing series of exposing the deaths of children from group homes. I left a career as a teacher after 17 years in 2020, because there were not adequate caregivers to care for my daughter. We just settled a lawsuit with the state last year. I spent days at the AZ State Capital with my daughter and other families speaking about and supporting the parents as paid caregivers program that Livingston from LD28 was targeting for cuts. A billion dollars has been spent on ESA vouchers, which started out as just for special needs families was switched in 2022 by the AZ legislature to include any family and by former governor Doug Ducey, which has had

widespread fraud due to the AZ Department of Education Superintendent Tom Horne not verifying money spent under 2,000, which after review, showed wasteful spending on non educational items. So, not only is what the federal government provides essential because it's 70 percent of our funding, but it is why I am running for AZ House of Representatives. In the long run, more money is saved by keeping disabled people independent living in their own home, then by placing them in facilities that tend to have high turnover and is more costly than having them in their own family homes.

My daughter is 24 and has issues communicating basic needs, so she cannot work a job. She will always require round the clock care and supervision. Cutting funding that goes to that care is beyond cruel and thoughtless. Our veterans, elderly, and disabled fall into a category that needs federal funding and that BBB sets out to put families and adults like my daughter in precarious situations of how to maintain quality of care for them. Republicans claim to be the party that supports families, but they don't want to care for them once they born and apparently, even as adults and don't see the hardship that this will cause people with disabilities and families. Families are already seeing loss of services, loss of providers, and I need direct providers that can care for my daughter.

I struggled as a single mom, educator, and mother of a high needs nonverbal child, but now I am aging and I afraid of the impacts of these cuts will have on her, our families, other families, and companies that provide support and care for her. The impact that cuts to Medicaid will have for adults like my daughter and others will have extremely negative impacts as it was challenging finding caregivers before the cuts and we already see people quitting.

Please do not do this to families and think about how you are hurting Americans. It took so long for rights to be given to the disabled and now Congress just wants to hurt disabled adults who cannot work. How is that making America great?

Guadalupe, Quintana, Douglas, Arizona

Dear Members of the Special Committee on Aging,

Community living matters to me

Therese Phipps, Tucson, Arizona

Dear Members of the Special Committee on Aging,

Community living matters to me because people and families of people with disabilities need

your help to live a safe and healthy lifestyle, they need advocates, without them they would be silenced, oppressed and the consequences would not only be demeaning but catastrophic.

Tiffany Griar, Rockville, Maryland

Dear Members of the Special Committee on Aging,

Community living matters to me because The Reason community living matters to me is that I have friends they are like.

Cynthia Christiansen, Tucson, Arizona

Dear Members of the Special Committee on Aging,

Community living matters to me because we look out for each other.
As a disabled elder, it has been the help of the State of Arizona which helped while raising my children to be productive, and educated members of society. My husband, legally blind, and I have been living within our SSD, and now SSI income, being off-grid and frugally surviving while raising our 3 children to become better educated. We still struggle, yet hold our family in high standings for helping others who are less fortunate than ourselves.

Debra Cook, Prescott Valley, Arizona

Dear Members of the Special Committee on Aging,

Community living matters to me because some aren't able to work.

Sarvesh Chandran, Chandler, Arizona

Dear Members of the Special Committee on Aging,

Community living matters to me because I enjoy being an active member of my community. I want to live with my parents in my parents' home. HCBS enables me to live with my parents, volunteer, and attend online college. I am able to utilize my skills and my education for advocating for people with disabilities. I love attending community events. I love to participate in adaptive recreation activities. HCBS enables me to live a wholesome and fulfilling life.

Thank you for your consideration.

DISABILITY RIGHTS ARIZONA

November 25, 2025

U.S. Senate Special Committee on Aging
United States Senate
Washington, D.C. 20510

Re: Statement for the Congressional Record on the Importance of Community Living Supports in Arizona

Dear Ranking Member Gillibrand,

Disability Rights Arizona (DRAZ) appreciates the opportunity to submit this statement for the Congressional Record for the Committee's upcoming hearing on the importance of community living for older adults and people with disabilities. As Arizona's Protection and Advocacy (P&A) agency, we see every day how essential Home and Community-Based Services (HCBS), Centers for Independent Living (CILs), and other community supports are to the independence, safety, and well-being of Arizonans with disabilities.

Arizona has long recognized the value of HCBS, and these services remain the backbone of community living in our state. Without reliable access to personal care, attendant support, habilitation, transportation, and other HCBS programs, many individuals face unnecessary institutionalization and loss of independence. CILs across Arizona further strengthen this system by providing peer support, skills training, advocacy, and transition services, especially in rural and underserved communities.

We also appreciate that Senator Mark Kelly, who serves on this Committee, has consistently demonstrated strong support for disability rights and the expansion of community-based services.

As you prepare for this hearing, we urge the Committee to prioritize federal investment in HCBS and in the independent living network. In Arizona, demand for these services continues to grow. Strengthening these programs will ensure people with disabilities can remain active contributors to their families, communities, and workplaces.

Again, we are grateful for your leadership and urge you to convey your colleagues in supporting these programs on behalf of the disability community.

Sincerely,



J.J. Rico
CEO
Disability Rights Arizona

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Arkansas

Sharon Wozniak, Conway, Arkansas

Dear Members of the Special Committee on Aging,

Community living matters to me because without it I wouldn't have a place to live. I also wouldn't have access to healthcare or medicine. Medicaid helps me live with my chronic conditions and I don't think I would survive if access to it was not available. My daughter is my full time caregiver and can't work out of the home. We are working with Medicaid to help get her paid so I can remain at home and not have to go to a nursing home. Without programs like these I believe many people would end up on the streets or even dead. Access to these programs are crucial for older disabled people like me. Please continue to fund and support these programs.
Thank you

Frank Hellmer, Benton, Arkansas

Dear Members of the Special Committee on Aging,

I am a person living with autism, and Home and Community Based Services like the Community and Employment Supports (CES) Medicaid Waiver I receive in Arkansas has enabled me to maintain a life in the community and a job as a data analyst for almost 6 years, especially when paired with the Arkansas Workers with Disabilities Medicaid program which allows for a Medicaid Beneficiary to keep their Waivers as long as they would be qualified for SSI otherwise. This enables me to have a much higher quality of life than I would have if I did not have HCBS to enable me to stay supported and in the community. In turn, I am able to have employer provided health insurance and a Flexible Spending Account, both of which help with my increased medical costs which would either be born entirely by Medicaid (and thus the taxpayers) or go untreated altogether, possibly leading to more expensive problems down the road. Also, HCBS gives disability service providers a means to provide jobs for their employees, including the direct care staff that they employ, as well as business for the various suppliers and vendors that they engage with in the course of business. As for me, thanks to my HCBS supports, on February 29 2024, I was able to come to Washington DC to testify before the United States Senate Special Committee on Aging about people with disabilities thriving in the workplace (https://www.aging.senate.gov/hearings/all-means-all-empowering-people-with-disabilities-to-thrive-in-careers-and-the-workplace) , and before that I had never flown on an airline before. Afterwards, I managed to complete my Master's Degree in Health Informatics from Arkansas Tech University, get promoted to Data Analyst 2, become chair of the Arkansas State Rehabilitation Council (https://dws.arkansas.gov/ar-rehabilitation-services/state-rehabilitation-council/), and travel to Seattle in October 2024 for an NCSRC conference. None of this would be possible for me or others with disabilities without HCBS supports.

Sheila Poarch, Redfield, Arkansas

Dear Members of the Special Committee on Aging,

Community living matters to me because. I need Medicaid and on SSI . It's hard to make it , but I appreciate everything I get help with! My community I live in is small and great! Please continue to help ! Thank you

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Phyllis Cox, Little Rock, Arkansas

Dear Members of the Special Committee on Aging,

I live in a low income retirement building. Some are hud. I do get help with my rent.
I have a daughter but would be unable to live there. Her house is full of stairs. And there is no room.
I live alone in a studio, but have many neighbors and we watch out for each other. I do my own cooking and everything in my house is gluten free as I have celiac Disease. I dont have steps here. Ramps and a elevator.
I honestly cant imagine where you want me to go. I would be homeless.
I've worked for 53 years. 10 hr days 6 days week.
What sir did I spend my life paying into these programs for. For you to call it a entitlement and just make it disappear.
We want our independence. A quiet corner to have as our own.
I have many illness. CAD, Celiac Disease, PBC and CSVD.
There is medication i cant live without. (forPBC) Cooking gluten free is also expensive.
Not everyone has the ability to save for retirement. I was a single mom.
Such a horrible thing to be told we dont deserve to live. I believe this is what our new government is telling us. Because we cant live without help.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from California

Debra Howell from San Rafael, CA

I suddenly became seriously physically and cognitively disabled in late December 1989 and could no longer work. I was homebound until I received my scooter thanks to Medicaid. I also had attendant care thanks to In-Home Supportive Services (IHSS), which is funded by Medicaid. My medical expenses were paid because of Medicaid. I received SSI and SSDI for much-needed income. About 3 years later, I was able to move into Section 8 housing, which stabilized me financially for the first time since I became disabled. Several years later, I was able to attend college and receive my degree thanks to Pell Grants and the CA Vocational Rehabilitation Department. For several months before I was deemed eligible for SSI/SSDI, I received food stamps, currently called SNAP. I received services related to attendant referrals, housing referrals, and a referral to CA VR Dept from my local Center for Independent Living. I was able to go to medical and other appointments, and attend college thanks to paratransit services and my scooter. Without these vital, essential services, I would not have been able to return to full-time work after 13 years. Most importantly, thanks to these services which enabled me to survive financially, physically, and cognitively, my stress was greatly reduced so that I could focus on a plan to live inter- and independently and ultimately return to full-time work. ALL people on Medicaid deserve to keep it, not just people who are able to return to work. But this is my story. If I had not had Medicaid, IHSS, SSI/SSDI, Section 8 housing, CA Vocational Rehabilitation Department and Center for Independent Living services, Pell Grants, food stamps, my scooter and paratransit services, I would have had to go to a nursing home, and I feel certain that I would have died there.

Maria Trombetta, Fort Bragg, California

Dear Members of the Special Committee on Aging,

We are writing to ask that you protect Medicaid's Home and Community-Based Services. Art Explorers, Inc. is a creative arts program and progressive studio in Fort Bragg, California, serving developmentally disabled and neurodiverse artists. When you walk into Art Explorers, you are immediately surrounded by the creative hum of art and art-making. Eight or nine artists sit at tables deeply engaged in making drawings, paintings, lino-cuts, ceramics, and textile arts. Staff members move between tables setting up art-making supplies and offering support to the artists.

Forty-two artists attend Art Explorers one or more times per week. For several of the artists, Art Explorers has been a vital part of their lives since its founding twenty-five years ago. Our mission is to provide a fun, nurturing, non-judgmental, and artistically stimulating environment for creativity to thrive.

We facilitate connections between the studio artists and the wider arts community through a guest artist program, field trips, and the exhibition and sale of artwork. Artists feel pride and fulfillment when they see their work exhibited at venues in the community and especially when they earn income from sales of their artwork.
"Making art makes me feel good," says artist Frank Van Curen. "I love showing my work off and talking to people about my art!"
The front of the Art Explorers studio is a gallery and shop where the general public can come in and buy original artwork, and reproductions created on greeting cards, t-shirts and other textiles. Once a month, we participate in the town's "First Friday" art walk, hosting an opening that brings the artists together with the public.

Thirty years ago, people with developmental disabilities were isolated in institutions or kept at home and were not seen as vital members of society. One of the main objectives of Art Explorers is to provide a pathway to inclusion in the wider community to our artists. Art Explorers is the only creative arts program in Mendocino County that serves a neurodiverse population.

Proposed cuts to Medicaid will severely impact the artists who work at Art Explorers. Art Explorer's mission is made possible by essential services that support the dignity and independence of people with disabilities. If our artists lose the daily living assistance provided through Medicaid's Home and Community-Based Services, their independence and mobility will be diminished. Reduced access to medication and healthcare will have a profoundly negative effect. Our program's funding by the Regional Center would likely be significantly reduced, meaning that we could serve fewer people.

"It would be hard to do things without the funding," says Van Curen. "I would just be bored at home. It makes me feel terrible to be stuck at home."

We don't want to go backward to a world where neurodiverse people are shut away from society and given second-class status. We want to continue to work for more integration of neurodiverse people in the community, with access to meaningful work, and an ability to express their unique perspectives.

Sincerely,

The Board of Directors of Art Explorers
Fort Bragg, California

Francis Kohler, San Francisco, California

Dear Members of the Special Committee on Aging,

Community living matters to me because I've worked as a DSP (Disability/Direct Service Provider) for over three decades, and I've seen firsthand the essential benefits that arise for people (with disabilities) who have opportunities to consistently be out in their communities while receiving the specialized support they require to live a full and vital life.

Jennifer Dokey, Thousand Palms, California

Dear Members of the Special Committee on Aging,

Community living matters to me because I care.

Daniel Hogue, Vallejo, California

Dear Members of the Special Committee on Aging,

Community living matters to me because the people I serve as the Executive Director of Las Trampas School, Inc. in Lafayette, CA deserve an equal opportunity to live independently just like their peers without disabilities. I have worked with the intellectual and developmental disabilities (IDD) community for over 32 years and have seen how people, when allowed to be a member of the community, thrive more than those in institutional settings and, as a result, pose less of a cost on taxpayers.

If services are lost or diminished, the costs to taxpayers will only increase and create a crisis for people with disabilities and encroach on their rights.

John Shillick, Concord, California

Dear Members of the Special Committee on Aging,

Community living matters to me because, it helps me live independently, have access to health and social services. I can see my friends and family. Without Medicaid HBCS, my long-term health care would be extremely expensive and unaffordable. I would become disconnected from my community which I do not want to happen. HCBS is the backbone of my life and I need it for stable living.

Stella Mancbo, Dorrian Collier, Nadia Gallo, Tamara Walker, Penny Ghiggeri, Leslie Gilmore, Jose Gonzalez, Cindy Tolentino, Marsha Kellog, Robby Hatmann, Eva Wright, Karla Marquez,

David Fitt, David Hein, Cherly Sutter, Andrea Halliday, Danielle Chinn, Kathy Lievore, Darren Keeffe, Sean Dunlap, Mikel Halperin, Clifford Turner, Matthew Bassett, Ronnel San Juan, Wyatt Bollinger, Sherri Krug, Ivy Iacopini, Concord, California

Dear Members of the Special Committee on Aging,

Community living matters to me because Helps keep me independent, allows me to live at home. I have access to health and social services. I can socialize with my friends and family. Without Medicaid HCBS, my long-term health care would be extremely expensive, and I would be disconnected from my community. HCBS is the backbone of my life.

Megan Benando, Concord, California

Dear Members of the Special Committee on Aging,

Community living matters to me because it's my job!!! i have been running a community Based program for 15 years. I have seen the improvements in the lives of my consumers by being in the community, working and socializing with not just their peers and coworkers with others. please make sure to keep programs like ours and support the people who support others!

Laura Martinez, Pleasanton, California

Dear Members of the Special Committee on Aging,

Community living matters deeply to me because, as a direct service provider for adults with disabilities seeking employment, I witness firsthand the profound impact programs like Medicaid HCBS have on their lives. Every day, I see how our program provides not just training, but real opportunities for independence and self-sufficiency. Being able to gain employment gives these adults a sense of purpose, belonging, and the ability to contribute meaningfully to their communities. Without programs like this, many of these individuals would face isolation, limited opportunities, and a diminished sense of autonomy. These programs don’t just support basic needs, they transform lives, fostering dignity, confidence, and hope.

Tracy Shortle, Orange, California

Dear Members of the Special Committee on Aging,

Community living matters to me because they bring joy and togetherness.

Lionel Botvin, North Hollywood, California

Dear Members of the Special Committee on Aging,

Community living matters to me because we all should live somewhere where others take care of one another and look out for us.

Jerry Otoole, Ventura, California

Dear Members of the Special Committee on Aging,

Thank you your support!

Erica Ponce, Moorpark, California

Dear Members of the Special Committee on Aging,

Community living matters to me.

Kim O`Reilly, Los Angeles, California

Dear Members of the Special Committee on Aging,

Community living matters to me because i can live in place where my piano is!
I don't know what i'd do without HCBS . . .

Rosalie Prieto, Bakersfield, California

Dear Members of the Special Committee on Aging,

Community living matters to me because it's important for everyone to feel safe, secure and taken care of.

Patricia James, San Jose, California

Dear Members of the Special Committee on Aging,

Thanks to Medicaid HCBS, I received respite support. It takes all my energy and time to take care of my daughter with CP, Epilepsy and some other diagnoses. Respite services restore my mental health, energy, and marriage.
Medicaid HCBS had also supported my family to pay for community activities for my daughter,

like swimming and dancing. She would not have joined and met people in the community without this support.

Cheryl Demmon, Vallejo, California

Dear Members of the Special Committee on Aging,

Community living matters to me because We have people in our own family disabilities. What is to become if they don't get Medicaid and home and community-based services? They deserve help, and should get it, so they can lead a full and healthy life.

William Volkmann, San Diego, California

Dear Members of the Special Committee on Aging Committee,

My name is Bill Volkmann. During my birth, I had a traumatic brain injury which resulted in cerebral palsy. I never questioned myself or my abilities, I always thought about the difference I could make in the world. I was enrolled in a school for children with intellectual and developmental disabilities. My mother noticed that I was excelling in all subjects and started asking the town in New Jersey if I could go to public school. Although she was met with harsh negativity, my mother never gave up; she had the help of ARC and when the ADA was passed, she asked the school board again— but got the same answer. She sued the school and won because of the ADA laws in place. My mother prepared me as best as she could, but I had to walk through those doors of my brand new public school without the real knowledge of what to really expect. I proved my mother right and continued to achieve both academically and socially. I was proof that it was possible for more students with I/DD to attend public school. I moved to Florida before high school. Again, I found myself in a small catholic high school, the only one with a disability. However, I still achieved success in and out of school, learning to drive and partying like the rest of my peers. My father had been diagnosed with Multiple Sclerosis before I was born and it got worse with age, but seeing what I had accomplished made him not give up and live his life in the best way possible. Shortly after I graduated high school, he had stage 4 lung cancer and passed away within the year. A few months following my father's passing, my mother found out she had leukemia. All while I was struggling with my own health due to cerebral palsy. Isolation set in not because of my mom's health issues or my own, but the loss of my community, school was always a great social atmosphere for me but I had been absent more frequently. Five years later, I lost my mother but I got my health back. I moved to Houston, Texas, near my sister. I was a college student and living on my own, but I realized that if you have a college degree it couldn't guarantee a job. I tried to work, but nobody would hire me. I joined the local church, but people wouldn't talk to me much. I turned to my friends and family in Florida, I had my community again, but the healthcare wasn't good for my Cerebral Palsy. I

moved back to New Jersey, where my other sister lived, for better healthcare. Again, I was met with the same thing as in Houston: Isolation. It came back even as I tried searching for employment and with the community. A few years later, my other sister moved to New Jersey from Texas because the education system would benefit her child with autism. He attended public school; being the first student with an intellectual and developmental disability allowed my nephew (and many others) to enjoy his life. In 2021, my sister who came from Texas, fell ill and passed away a year later. I took care of my nephew while she went back to Houston in search of getting better healthcare. I had first-hand experience raising a teenager with autism. In 2022, I decided to follow my dream and move to San Diego. I didn't know anyone there, but I knew the weather and healthcare were much better there. I went to work volunteering at two foundations, even though this was different from other places I volunteered at in the past. San Diego was more accepting and saw me as Bill, not my disability. I was told about the regional center and I didn't know what to expect. In 2023, I became a client and was in awe of all the things I was offered. Their goal was to have everyone with an intellectual or developmental disability be like everyone else in California. For the first time in my life, I felt like I could have the life I always wanted; nobody had to worry about time or money and more importantly, I felt in control. I enrolled in the Self Determination Program that gave me the most choices. I am now able to live a healthy and safe life, going out when I want, day or night. Living where I want to live because of my needs, and knowing I will be taken care of with respect throughout my life. Since a significant amount of funding comes from Medicaid HCBS funding programs that I rely on for supportive living, which helps me live independently in my own home, and the people who enjoy the community and culture with me. I've had Supportive Employment for almost my whole adult life, and have dreamt of being a business owner. I'm determined to make it happen. I am grateful for all the therapeutic activities I get to partake in; I need to keep myself healthy, strong, and pain-free. This funding matters to me and many others. I don't want to go back into isolation; I want to help others with all kinds of disabilities be fully included in society. American society can benefit a great deal from a fully inclusive society regarding people with disabilities.

To me, this isn't a political, religious, or sociological-economic issue; it's a moral one. Disability doesn't see those issues; it affects everyone. It's also a human issue. How are we going to treat our fellow Americans who do their best every day? We need to stop kicking people down who are trying to make their lives better. The funds affect real people with their own hopes and dreams. As Americans, we should be cheering for them.

Ken Donohew, Ellen Kippel, Oceanside, California

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities and older adults deserve to live

with independence, dignity, and connection to their communities. Make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.

Christina Watte, Upland, California

Dear Members of the Special Committee on Aging,

Community living matters to me because our son, Mike deserves emotional support of family and having his family involved to advocate for him. The family needs to ensure care plans are effective. Mike has grown up with his sisters and their friends and the rest of our extended family. This has helped him grow as a human being. Mike enjoys interacting with his friends at his day program. He often helps those in wheelchairs making him feel useful. He also goes out in the community showing the public that those with developmental disabilities can do "normal" things.

Deborah StJulien, San Jose, California

Dear Members of the Special Committee on Aging,

Community living matters to me because my niece has Downs and participates in an ARC program in Upstate NY.

Annajean Morales, Queens, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because we are united

Cristina Sheppard, Concord, California

Dear Members of the Special Committee on Aging,

Community living matters to me because we need the support.

Beverly Harris, Fairfield, California

Dear Members of the Special Committee on Aging,

THIS IS TRULY NEEDED Community living matters to me because for those that need HELP NOW

Dan Okenfuss, Sacramento, California

Dear Staff of the US Senate Special Committee on Aging:

I understand you are collecting stories from people with disabilities and older adults about Home and Community-Based Services (HCBS), Independent Living Centers (ILCs), and other services and supports that help people go to school or universities, find and maintain employment, and participate in their communities. I also understand the submission deadline for stories to be counted as part of the public record after the hearing is Monday, December 8th at 3:30 pm eastern.

On behalf of the California Foundation of Independent Living Centers (CFILC), I am sharing these stories from our consumers with disabilities who reached out to our network for assistance in securing HCBS for their health and welfare at home.

Consumer #1

One of our independent living centers in the SF Bay Area assisted a consumer who had been attacked with a weapon in 2020 and is currently following up on the case. The ILC assisted the Consumer by contacting the Sacramento Victim Compensation Board office to inquire about the application process for the mental health relocation verification form. Additionally, the Coordinator contacted his primary care doctor to request a referral to a psychologist, ensuring he receives the necessary mental health support.

Consumer #2

One of our independent living centers in the SF Bay Area went to a skilled nursing facility (SNF) in Hayward to assist a consumer with reading her correspondence. The Consumer had difficulty hearing but hearing aids had already been ordered for her. Additionally, she had trouble seeing well enough to read. We also contacted Medicare to inquire about the medication program she is enrolled in.

Consumer #3

Sheilla is a consumer who came in from the Marin One Door. Sheilla was stable with her housing until her roommate moved out a couple of years ago and left her in a home where she was solely responsible for the rent and without any supports that she was getting as a byproduct of living in a shared space. Sheila was resistant to moving out of her home, even though she couldn't afford it, until she was evicted. The AAA connected her to St. Vinney's who helped her move her into a new apartment, paid her move in cost, and paid to get many of her belongings into a storage.

Consumer #4

This success story is about a couple of Vietnamese consumers who are husband and wife and their adult daughter who is their caregiver. About 1-1/2 years they connected with our Vietnamese SW Joseph, who signed them up for MOWs IHSS, and provided them with referrals for assisted transportation. They were extremely happy to be working with someone who spoke their language and reported that they had been trying to get help for years, off and on, but because of the language barrier and other challenges, felt they would never get the help they needed. Joseph started in the unit because of community advocacy for a bilingual Vietnamese/English speaker, so it was satisfying for us to see this outcome.

Consumer #5

Clayton, a 38-year-old resident of Mill Valley, CA, has been navigating life with a traumatic brain injury (TBI) since he was 13. As a longtime client of Golden Gate Regional Center (GGRC) and Integrated Community Services (ICS), he sought a stable living situation that could accommodate his needs. MCIL played a crucial role in securing housing for Clayton, helping him transition into a one-bedroom unit where a staff member could stay overnight to assist him, as he experiences frequent seizures. Additionally, MCIL facilitated the process of obtaining a dependable In-Home Supportive Services (IHSS) caregiver and became his signatory, ensuring he had reliable assistance for essential daily tasks such as grocery shopping, meal preparation, and attending medical appointments. Today, with a strong support system in place, Clayton enjoys greater independence and a significantly improved quality of life.

Consumer #6

Debra, an 83-year-old resident of Novato, CA, was referred to MCIL by the Marin County Ombudsman. Facing challenges in accessing care and resources, she needed guidance to secure essential services. MCIL assisted Debra in successfully applying for Medi-Cal, obtaining a free phone through the California Lifeline program, and navigating the complexities of her long-term care insurance. With MCIL's support, she was able to move into an assisted living facility of her choice in Marin County, where she now enjoys a safe and comfortable environment.

Please let me know if you need more information from CFILC.

Best wishes,

Dan

Kathleen Nichols, Anaheim, California Dear Members of the Special Committee on Aging,

Community living matters to me because my brother has down syndrome and community-based services have had such an amazing impact on his life. He was lucky to be born in 1976 and by that time, society had realized incorporating people with disabilities in our lives is better than institutionalizing them. My brother is a thriving member of his community because of HCBS

programs. If he did not have this support, I'm not sure what there is for him. He cannot live or work independently but he can thrive with community support based system. Without these programs my brother and many like him will suffer greatly. The cost of these community services benefits the entire community and should be borne by the entire community. If we go back to institutionalizing disabled people, it will be a dark time for our country (not to mention a waste of time and resources to do so).

Barbara Petsuch, Vallejo, California

Dear Members of the Special Committee on Aging,

Community living matters to me because I have worked with people with intellectual and developmental disabilities for over 20 years. This population wants to work and be a part of their community. Funding's that are cut to this population would be heartless. I agree cuts should be made and there are many people utilizing the services that could work and do better for themselves, however this population is doing the best they can. The services that are provided through Medicaid are essential for them to live and work and be apart of their communities. Please reconsider on cutting any funding that goes to the IDD community.

Claire Jones, Lenmoore, California

Dear Members of the Special Committee on Aging,

Community living matters to me because I am still Able to participate and contribute to the overall well being if the community. We either live together in safety or the community is deprived of a valuable source of support for the others.

Ernesto Barajas, San Lorenzo, California

Dear Members of the Special Committee on Aging,

Community living matters to me because
I'm part of the community

Hamid Shiwoku, Inglewood, California

Dear Members of the Special Committee on Aging,

Community living matters to me because, you lived with your own and that means much to the elderly people.

Philip Lefcourt, Pasadena, California

Dear Members of the Special Committee on Aging,

If it weren't for Medicaid/Medi-Cal, I would be homeless or living in a shelter!! Thank God for Medicaid/Medi-Cal!!!

Llll D. Oakland, California

Dear Members of the Special Committee on Aging,

Community living matters to me because
People Need communities!
People Need connection!
People Need social services!
People need one another!
People ARE COMMUNITY

Ryan Schrader, Bellflower, California

Dear Members of the Special Committee on Aging,

Community living matters to me because it is essentially important for everyone to have access to the living in their communities.

Eric Devezin, San Jacinto, California

Dear Members of the Special Committee on Aging,

November 21, 2025
To: United States Senate Special Committee on Aging Re: Hearing on the Importance of Community Living and Medicaid HCBS
Dear Chairman Casey, Ranking Member Braun, and Members of the Committee:
My name is Eric Anthony Devezin, and I am writing to you as a member of the In-Home Supportive Services (IHSS) Public Authority Advisory Committee in Riverside County, California. I am also a Doctor of Public Administration student focused on equitable community health policies.
I am submitting this testimony on behalf of the seniors, persons with disabilities, and care providers I represent to emphasize that Medicaid Home and Community-Based Services

(HCBS)—known in our state as IHSS—are not just a benefit; they are a lifeline that upholds the civil rights of our most vulnerable citizens.

As an Advisory Board member, these programs impact my life by defining the health and stability of the community I serve. I work daily to bridge the gap between complex policy and the human beings who rely on it. Medicaid HCBS allows the people I represent to remain neighbors rather than becoming statistics in an institution.

In my work, I see that HCBS is the infrastructure of dignity. It allows an 85-year-old to age in the home they built, rather than a strange facility. It allows a person with a disability to pursue education and employment, contributing to our local economy. For me, living in a community that cares for its own—where independence is supported by policy—is fundamental to a functioning society.

If we did not have Medicaid HCBS/IHSS, the consequences would be catastrophic for my community:

1. Without the support of direct care workers to help with activities of daily living (eating, bathing, and paramedical care), thousands of seniors in my district would be forced into nursing homes. This is not only contrary to their wishes but is also significantly more expensive for the taxpayer than home-based care.

2. Without paid caregivers (many of whom are family members supported by these programs), working-age adults would have to leave the workforce to provide unpaid care, driving families into poverty and removing vital labor from the economy.

3. The removal of these services would signal that we value efficiency over humanity. It would strip our elders of their autonomy and sever their connection to the communities they helped build.

We cannot talk about "community living" without funding the workforce and the programs that make it possible. I urge Congress to protect and expand funding for Medicaid HCBS. We must ensure that direct care workers receive a living wage and that seniors have the right to choose where they live.

Thank you for your time and for elevating these essential stories.

Sincerely,

Eric A. Devezin, Member, IHSS Public Authority Advisory Committee: Riverside County, California.

Janet, Heinle, Santa Monica, California

Dear Members of the Special Committee on Aging,

Community living matters to me because we need to there for each other, it is important in this technological age

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Danielle Rose, El Cajon, California

Dear Members of the Special Committee on Aging,

Community living matters to me because as a care provider the residents in our home are treated with dignity and respect. They have the support the need to live quality lives like everyone else and they deserve that happiness. It saves the system to do things the right way instead of mass institutional settings that cause damage and harm to their well being.

Don Watte, Upland, California

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows my 49 year old son with Downs Syndrome to live a healthy, productive, fulfilling happy family life.

Aditya Joglekar, Walnut Creek, California

Dear Members of the Special Committee on Aging,

Our younger daughter, Ila, (now 11) has Cerebal Palsy. She is non-verbal and has learning delays, along with other medical conditions from the time of her birth. We discovered the Community-based program, VistAbility, just within the past year. And already, in less that 8 months, VistAbility's George Miller Center has proven to have a tremendous impact on her in terms of her social development, and access to life skill learning opportunities, and a sense of belonging that she does not receive in school. With programs like VistAbility, we see a long term path ahead for Ila, where she can continue to learn and grow with her peers, to continue to develop new skills reinforcing what she is taught in school, and ultimately contribute to society through work and education programs. We have already seen that if this program did not exist, Ila's social development, life skill learning, and access to her community would be severely negatively impacted, and her personal growth would be hindered as a result. We hope and pray that our Government and Congress continue to support Home and Community Based programs like VistAbility for the benefit of all of our citizens and community members like Ila.

Karen Reside, Long Beach, California

Dear Members of the Special Committee on Aging,

Community living matters to me because, cynde Soto our vice president, who is totally disabled

and dependent on MediCal for her life, just helped get $10,000 for grocery gift cards for older adults in our community for grocery gift cards. Even though totally disabled, cynde has connected us with other other
Organizations to benefit our community. She provided input in designing our program to include disabled seniors so all older adults would receive benefits. She is an amazing connector and advocate.

Doris McDermott, Menifee, California

Dear Members of the Special Committee on Aging,

Community living matters to me because I have serious hearing issues 70% in left ear and 80% in right ear and will soon have to have cochlear implant in right ear. I am wearing hearing aids but they don't help much. My hearing loss is making driving dangerous for me. My hearing loss is creating problems with my vertigo and I have fallen 3x since June 2025. Fractured my right foot and had to wear a boot for a while this summer. I ain't Wonder Woman anymore!!!!

Stacie Charlebois, Sebastopol, California

Dear Members of the Special Committee on Aging,

Community living matters to me

Barbara Letsom, Escondido, California

Dear Members of the Special Committee on Aging,

Community living matters to me because I live in a senior community of over 300 people with disabilities and/or over 55. Collectively we all give and receive services from the wider community of Escondido. Many of us depend on services for survival or quality of life.

Patricia Goodson, Clearlake Oaks, California

Dear Members of the Special Committee on Aging,

Community living matters to me because it creates a social support for seniors

---

Dorothy North, Berkeley, California

Dear Members of the Special Committee on Aging,

I am not disabled myself, but my older sister has mental health issues and lives in a community setting. It has helped her enormously, but cuts to these services and SNAP are likely to have a big negative impact on her life, and I am very concerned. These programs are enable her to be independent, which is very important to her.

Charlene Naumec, Bakersfield, California

Dear Members of the Special Committee on Aging,

Community living matters to me because without it I wouldn't have my home my health and my peace of mind. There are so many cuts to programs that make our lives better. It makes us feel stronger and happier and more productive

---

Karen Lobel, Santa Cruz, California

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a disability called Cerebral Palsy, which is injury at birth. I have been lucky to have an independent life, but my disability puts me in a lot of pain, as a younger person, having the services of In Home Support Services made the difference in my ability to live in my own clean, sanitary home. Now that I am 82 years old, and unable to take care of myself in any way, the care I received from IHSS is the only thing that keeps me from being stuck in a bed somewhere and left to die. I'm just one of thousands of people to depend on these services.

Shirley Surney, Pittsburg, California

Dear Members of the Special Committee on Aging,

Community living matters to me because if I need to be seen by a medical doctor it is very important to have insurance without it is to costly for me to pay out of pocket. I am very active in my program at Vistability. This will help me to continue participating in my program.

Mitzi Diaz, Concord, California

Dear Congress,
My name is Mitzi and I am a direct support service worker who knows many people who receive Medicaid. Without the funding of Medicaid many of these people would simply not be

able to live. The harsh truth is many individuals are born with life-altering disabilities through no fault of their own. Medicaid provides medical care for so many who cannot afford to pay for it on their own, they have disabilities that exclude them from being able to work and fund their own lives. I do not believe that they deserve to have this funding removed and genuinely believe we would see thousands of people die due to this action. Please keep an open mind and open heart and remember that caring for those who cannot care for themselves is the least we can do.

Crystal Joseph, Antioch, California

Dear Members of the Special Committee on Aging,

Community living matters to me because I hate being isolated and depressed. I think it's a basic human right. Not going into the community is like being in prison. Would you want to be locked up?

Francis Johnson, San Mateo, California

Dear Members of the Special Committee on Aging,

Community living matters to me because I know someone who has multiple sclerosis and can barely walk on his own. He lives in a low income retirement community, can't work so can't make income, and depends on SNAP and Medicaid. He barely gets much SNAP support, so I make sure I help out by making him home cooked meals at least once a week. He can't afford living in a nursing home and if he loses his housing he currently resides in he will be living on the streets.

Linda Morgan, Folsom, California

Dear Members of the Special Committee on Aging,

Community living matters to me because I am blind, deaf, and have balance challenges. I am a 66 year old woman with Usher's Syndrome 2a. It is a genetic disease causing blindness, deafness, and a loss of balance ability. I was born deaf and went legally blind at 58. I cannot live alone. I cannot see, hear, or walk unassisted. I worked until I went blind and now receive SSDI. I know President Trump wants me to just die, but I am actually a functioning member of society with assistance. I contribute to the economy, am active politically, volunteer with children groups, and am helping raise my granddaughters. The strong daughters I raised are a OT and a physician, both contributing members of society. Please continue to support assistance for the disabled. I actually don't need community living, but if I did not have my family, I certainly would. I would die without assistance from other people. I am extremely grateful for kindness.

Evelyn Picnick, La Quinta, California

Dear Members of the Special Committee on Aging,

My home has two people living in it with disabilities. Myself which is from age and my granddaughter who has down syndrome and nonverbal. My granddaughter needs more help than I do. If she didn't have some of these services she wouldn't have bad or a chair. They have provided that and they have made it so that it's wonderful that she can grow with it. I really need some bars on my shower so I can get in and out of it. I do find it hard getting around the community and I do wish that they were more willing to help elderly than they are

---

Cassidy Pedersen, Pittsburg, California

Dear Members of the Special Committee on Aging,

Community living matters to me because there are so many people in my community who depend on this. Many of us cannot afford the costs of living without some additional support, because wages and laws have not adjusted for the increasing prices all around. Without these services, many people would be forced to pay out of pocket for healthcare. This might not even be possible for some individuals who can barely afford rent as it is, which would leave many people at risk of experiencing homelessness. Please protect my friends, family, and community by funding these programs and services.

Afiya Wilkerson, Antioch, California

Dear Members of the Special Committee on Aging,

Community living matters to me because my elderly mother receives these services and without them she wouldn't be able to make it. We need our representatives to stand up for people like my mother. She worked all her adult life teaching others and she deserves to live the best life for all her hard work.

Jonathan Santillan, Concord, California

Dear Members of the Special Committee on Aging,

Community living matters to me because s, loss of insurance coverage, and loss of home and community-based services for people with disabilities across the country. Thanks to the

Lanterman Act's assertion of community-based services as a right for Californians with disabilities.

Malcolm Moore, Portola, California

Dear Members of the Special Committee on Aging,

Community living matters to me because less fortunate people need care community cn prove, with proper funding

---

Daniel Okenfuss, Sacramento, California

Dear Members of the Special Committee on Aging,

Community living matters to me because I work for the California Foundation for Independent Living Centers (CFILC), whose mission is to increase access and equal opportunity for people with disabilities by building the capacity of Independent Living Centers.
We serve over 26,000 individuals with disabilities, providing over 160,000 services to help them reach their goal of living independently.
Most of these individuals with disabilities are on Medicaid, so it is crucial that federal funding is maintained to accommodate their immediate care needs. Without this investment, our consumers could lose everything and become homeless or forced into institutional care facilities - both options that put more strain on scarce resources in their communities.

Ron Burkhardt, Santa Monica, California

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. HCBS help make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.

I sit on the Board of New Horizons in North Hills, CA. This 70 year old organization has been providing critical services to this neurodiverse community and is highly successful in doing so!

If you cut funding these critical servies will diminish and then what?

Do not let this happen and do the right thing!

Nikki Diaz, Los Angeles, California

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm an intelligent, free thinking, self decisive with person centered goals who should be left to thrive and participate in a neighborhood /community of my choosing. I am a participant of several interest groups. Diversity modeling, songwriters and arts & media group for writers and authors.
If I didn't have the HCBS program I would have to limit my toileting and eating times to only twice a day. I would not have the ability to socialize, meet with my groups of interest or commit to my creative works. I would have no caregiver to be with me at night which is critical to my medical health sustainability.
These details may seem versatile in how to handle them. But it's truly about my human right to thrive in a country that permits me to be free.

James Cheng, Saratoga, California

Dear Members of the Special Committee on Aging,

Community living matters to me because of my working habits. It also makes me eat dinner at home

---

Maria Rivera, Fresno, California

Dear Members of the Special Committee on Aging,

Community living matters to me because continue services I need like keeping up affording health care and doctor visits, finishing up my college education and standing strong living independent afford housing in the future.

Angelica Gonzalez, Pittsburg, California

Dear Members of the Special Committee on Aging,

Community living matters to me becauseI have a 17 year old son with special needs and when he becomes 18 even though an adult he will still need services to help him learn to manage his condition and lead his best life I an low income and if not for these services what would one do . Please keep the services disabled people need

---

Barbara Kaplan, Oakland, California

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a 77 year old woman who has lives with a serious chronic illness for more than 23 years. It keeps me home bound, often bed bound. Yet my home is my haven, where I have constructed a life worth living. Without programs like Medicaid HCBS, people like me are shuttled into group homes that do not provide the right to happiness that our constitution should protect. Then life is not worth living. Please, so not relegate us to living hell at a time when we most need love and support!

Ryan Duncanwood, Redding, California

Dear Members of the Special Committee on Aging,

Community living matters to me because my parents can't support me

---

Diamond Bell, San Francisco, California

Dear Members of the Special Committee on Aging,

Community living matters to me because it enriches everyone's life. Living with my brother has taught me so many important lessons and has given me great joy.

Cliff Atendido, Burlingame, California

Dear Members of the Special Committee on Aging,

Everyone deserves some type of medical care

Derek Moss, Anderson, California

Dear Members of the Special Committee on Aging,

Community living matters to me because we are a community...

Hunter Christian, Poway, California

Dear Members of the Special Committee on Aging,

Community living matters because it truly allows marginalized and overlooked members of our community attain life goals, broaden their horizons and truly create belonging, friendships and often times find meaningful and productive positions. Please take look at our model - we are an affordable, all disabled public housing community. We have been open for almost 5 years, serving 60 residents...extraordinarily successful. There need to be more opportunities for this type of success. www.villadevida.org

We cannot provide these services and housing without Medicaid and HCBS - this is the very definition of these services.

Stephanie Hart, Costa Mesa, California

Dear Members of the Special Committee on Aging,

Community living matters to me because everyone deserves a safe place to call home

---

Jennifer Alonso, San Diego, California

Dear Members of the Special Committee on Aging,

Community living matters to me because I am part of these communities and want others around me to be happy, to cultivate healthy relationships!

Sean Nealy, San Diego, California

Dear Members of the Special Committee on Aging,

this sean nealy see try back in uour progms try work at mcrd

Nestor Ocano, Escondido, California

Dear Members of the Special Committee on Aging,

living matters to me because people with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. HCBS help make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.

Amir Baum, Aliso Viejo, California

Dear Members of the Special Committee on Aging,

Community living matters to me because my aging parents are going to need all the help and support they can get as they move to their 80s and taking away that support net is beyond cruel, evil, callous and sick!!!

Sandina Mayberry, Knights Ferry, California

Dear Members of the Special Committee on Aging,

Community living matters to me because I have seen first hand how difficult life can be for those with health issues. The elderly are far more vulnerable to loneliness and despair because of isolation. Programs like Medicaid HCBS and Medicare help those in our communities who need the most help. Do not eliminate these programs.

Lori Linberg, Palo Alto, California

Dear Members of the Special Committee on Aging,

Community living matters to me because I worked for many years for seniors people and with special needs. When you are sincerely, disabled, it is a sign of our humanity to help those who need it. A family that has a severely disabled member, cannot work if they need to take care of them every day. They are overwhelmed with expenses and difficulties, the least we could do is give them a hand as humans. Many people who sincerely need these services do not even know how to access them and do not take advantage of it. If we can provide in-home services, we can save money creating and sending them institutions. The institutions of the past were rather inhumane and very expensive, as I worked in one for many years. Giving honest disabled persons and families a hand at home, keeps family caregivers able to contribute to society, whereas without the help they would not be able to.

Can you imagine what it is like to have a family member who has become a total dependent and you don't have the money to pay for help and you have to stay home to take care of them? In today's economy, you would never survive without a helping hand. We have always honored our humanity with compassion to those less fortunate. Do we really want to end our definition of humanity? To be or to have a family member who you love to be in such need of help is a heart broken burden by itself, why must we add to it? As we study our history, we have always noted that the sign of humanity is the helping hand, let us continue it. If we decide we cannot do that

anymore, then we must open the doors to euthanasia because if we can help the people who can help themselves, we might as well not let them suffer. Please may we fight to maintain our humanity and treat people with equity, as we stated in the constitution. By giving a helping hand, we create equity which these people cannot have if they have the burden of being in need themselves or the burden of being the caregiver. Have we lost our hearts because it didn't happen to us and what would we do if it was us? I understand we have to skim off the people who take advantage of things, but the system is hard enough as is. To add to the difficulties creates a society of cruelty and a lack of equity. Just because you are disabled or a family member is disabled Have we come to decide that the disabled are worthless and don't deserve a roof over their head, healthcare, and food.

I have spent many years of my life, helping the aged population, due to illnesses, such as ALS, Huntington's disease, Parkinson's disease, strokes, cancer, and dementia, inside each of these people remains a human who has loved and given so much to society. How can we decide that they are worthless now or the family that is burdened with caring for them doesn't deserve help. I watched many people struggle to get the simplest of things presently from the government who deserved it 150%. Please don't take away any more benefits from those of us who are not as fortunate.

I am presently disabled after over a 30 year career and I purposely have not gone after disabled services because I understand that the system is so difficult, and overtaxed. Somehow I manage and I do without because it means so much to me that those who sincerely deeply cannot do anything for themselves can get the help they need. As a senior, I saved money for my retirement, but the cost of living has become so expensive that of course it is not enough money for the seniors in America anymore. The cost of housing has skyrocketed, leaving many seniors, not being able to afford a roof over her head never mind with a Disability. How can we throw our mothers and fathers and grandparents to the streets and then complain about them being there. Offering meals on wheels help for food and help for a roof over our head and need healthcare seems to me to be a sign of a healthy society. People are living longer and with that it increases the chances of people not being able to care for themselves and needing help. Keep humanity alive, please. Continue the benefits and make it easier for those people who really need it. We cannot be a healthy humanity if we do not care about our fellow man.

PLEASE EXCUSE MY TYPOS, I HAVE A 70% LOSS OF USE OF MY HANDS IS VERY DIFFICULT FOR ME TO TYPE CORRECTLY AND UNFORTUNATELY USING THE MICROPHONE DOES NOT ALWAYS WORK CORRECTLY

Kimberly Bostrom, Alameda, California

Dear Members of the Special Committee on Aging,

Community living matters to me because I believe in diversity as a means to a richer public life. Everyone has their own unique talents to contribute and gifts to share.

Christina Hart, Folsom, California

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a developmental disability called "autism," and I'm a transgender woman named Christina Hart. I live in California. I'm 34-years-old. My disability services at home in California pay for my ballet classes and guitar lessons. I'm a musician and ballet dancer. Please don't take away my days at my ballet class and guitar lessons.

Please don't take away my rights to have a part-time job and do my paid hobbies that are my ballet classes and guitar lessons.

I create and sell my country and Hawaiian music albums and singles online to audiences in Australia and the United States on iTunes and YouTube using my TuneCore account. I promote my country and Hawaiian music albums and singles to audiences in Honolulu, Hawaii on Facebook for $20 for 5 days, so people in Honolulu, Hawaii can buy my country and Hawaiian music albums and singles on iTunes. Please don't take this away from me.

Please support disabled and LGBTQ+ people like me, our lives matter. Disabled and LGBTQ+ people are two special global communities of people, we can do anything and we can go anywhere, we have the power and the potential, we are strong and united people, we are self-advocates. I'm a self-advocate. We are doers and we are winners and we are the champions and the warriors.

Donna Ross-Jones, Los Angeles, California

Dear Members of the Special Committee on Aging,

Testimony for Senate Special Committee on Aging
The Life-or-Death Importance of Medicaid Home and Community-Based Services

From: Donna Ross Jones, CEO, Transition Music Corporation; Co-Founder, Special Needs Network

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How do programs like Medicaid HCBS impact your life? What would happen without them?

My son Nick is 27 years old. He has Level 3 autism and requires 24/7 supervision. Without Medicaid Home and Community-Based Services, he would not be living at home with dignity, purpose, and connection to his community. He would be warehoused in an institution, and our family would have been financially destroyed decades ago.

This is not hypothetical. This is the reality for millions of American families.

The Math That Doesn't Work Without HCBS

When Nick was diagnosed at 24 months in 2000, I was told what every parent of a child with severe developmental disabilities hears: your child will need intensive, lifelong support. What they don't tell you is that without federal programs, the annual cost of that support can exceed $47,000-$70,000 per year - and institutional care costs even more, averaging over $47,000 annually compared to approximately $36,000 for community-based services.

No middle-class family can afford that. No working-class family can afford that. Without Medicaid HCBS programs, families face an impossible choice: bankruptcy or institutionalization.

I know this because I've lived it. Even with HCBS services, our family faced business collapse, financial devastation, and divorce under the strain of coordinating Nick's care. But those federal programs - the respite care, the day programs, the supported living services, the personal care attendants - those programs are what kept Nick in his community instead of locked away in a facility.

The Ripple Effect: How Cutting HCBS Destroys Economic Productivity

Here's what legislators need to understand about the economic cascade when HCBS programs are cut or inadequate:

Nick needs care.
Without HCBS day programs and support services, I must provide that care 24/7.
When I'm providing 24/7 care, I cannot work.
When I cannot work, I stop paying taxes.
**When I stop paying taxes, I stop being a taxpayer and become someone who needs

assistance.**

Now instead of one person needing services, you have TWO people needing public support, PLUS the lost tax revenue from a productive worker forced out of the economy.

This isn't theoretical - the data is staggering:

According to research, parents of children with disabilities are three times more likely to make career sacrifices than parents of children without disabilities. Among parents with autistic children specifically, 55% report they have reduced work hours or quit their jobs entirely.

Caregivers of children with disabilities lose an average of $18,000 per year due to scaling back work hours or leaving jobs. Mothers of children with autism earn 56% less on average than mothers of children with no health limitations.

International studies show that the more severe a child's disability, the more likely the mother is to reduce work hours, earn less income, or stop working entirely.

Multiply this by hundreds of thousands of family caregivers across America. HCBS programs don't just help people with disabilities - they keep family caregivers in the workforce, paying taxes, contributing to the economy, and maintaining their own independence.

The false economy of cutting HCBS is staggering. You save $30,000 on day program funding and lose a $75,000 taxpayer. You eliminate a $40,000 respite care budget and create a $60,000 public assistance case. You defer HCBS services and pay triple for institutional care plus emergency room visits.

I run a company. I employ people. I pay taxes. I contribute to my community. I can only do this because HCBS services exist for Nick. Without them, I become another person dependent on public assistance, and my employees lose their jobs too.

This is not just about compassion - it's about basic economics.

What HCBS Actually Means in Real Life

Let me tell you what Medicaid HCBS looks like in practical terms:

It means Nick can participate in day programs where he learns life skills, socializes with peers, and contributes to his community through supported work activities. Without HCBS

funding, these programs wouldn't exist or would be financially out of reach.

It means respite care that gives family caregivers the ability to work, to care for other children, to maintain their own health. Without HCBS, I couldn't have maintained my career or supported my neurotypical daughter Evyn. The entire family would have collapsed under the weight of 24/7 caregiving.

It means personal care attendants who are trained to support individuals with complex needs, preventing medical crises and emergency room visits that cost taxpayers far more than preventive community-based care.

It means supported living services that teach and maintain essential daily living skills, reducing long-term care costs and maximizing independence.

The Alternative Is Cruel and More Expensive

Here's what policymakers need to understand: institutional care for people like Nick costs taxpayers MORE than community-based services, while delivering objectively worse outcomes. According to recent data, institutional care averages over $47,000 annually per person, while HCBS averages approximately $36,000 - yet people in institutions:

- Experience higher rates of abuse and neglect
- Have shorter life expectancies
- Show increased psychiatric problems from isolation
- Lose skills they previously had
- Are separated from families and communities

Meanwhile, HCBS programs that keep people in their communities cost less while providing demonstrably better quality of life.

This Affects Millions, Not Thousands

Through my work with Special Needs Network and my blog "Autism Day by Day," which has reached over 3 million readers, I hear from families across America every single day. Their stories are identical to mine:

- Parents who can't work because there's no day program funding
- Families bankrupted by private-pay services when HCBS waitlists stretch years
- Young adults with disabilities aging out of school services and falling off a cliff into

nothingness because adult HCBS services don't exist or are underfunded
- Siblings forced to sacrifice their own education and careers to provide unpaid care
- Parents in their 70s still providing 24/7 care because no community services exist for their adult children

The Urgency Is Now

I've testified before congressional committees. I've advocated at state and federal levels for over two decades. I've built organizations, created resources, and educated millions of families navigating these systems. And I'm telling you: the HCBS infrastructure is fragile.

States have massive waitlists for HCBS waiver programs - over 700,000 people across 38 states are waiting, with average wait times exceeding 5 years. Direct care workers are leaving the field because Medicaid reimbursement rates don't allow providers to pay living wages. Day programs are closing because they can't sustain operations on current funding levels.

If we don't strengthen and expand Medicaid HCBS:

1. **Families will be destroyed financially and emotionally**
2. **People with disabilities will lose the community integration they've fought for**
3. **The costly institutional system will expand again**
4. **Taxpayers will pay significantly more for worse outcomes**
5. **We will abandon the most vulnerable among us**

What Success Looks Like

Nick is 27. He lives with dignity. He participates in his community. He is known, valued, and supported in his neighborhood. He attends programs. He has relationships. He is not hidden away.

This is only possible because of Medicaid Home and Community-Based Services.

Multiply Nick by millions - because that's how many people with intellectual and developmental disabilities, older adults, and people with physical disabilities depend on these programs to live with the independence, dignity, and community connection that every human being deserves.

Programs like Medicaid HCBS are not "nice to have." They are the difference between dignity and warehousing, between community and isolation, between fiscal responsibility and financial catastrophe.

I urge the Senate Special Committee on Aging to not only protect these programs but to expand them, strengthen them, and ensure that every American who needs community-based support can access it.

Donna Ross Jones
Parent, Author
CEO, Transition Music Corporation
Co-Founder, Special Needs Network
Author, "Autism Day by Day" (blog, 3M+ readers)
Mother, Advocate, 25+ Years Navigating Disability Services

Willie Reed, Concord, California

Dear Members of the Special Committee on Aging,

Community living matters to me because they are a part of the community and should be recognized and accepted as such.

Miko Baker, Patterson, California

Dear Members of the Special Committee on Aging,

Community living matters to me because I support individuals with developmental disabilities for a living. I see their financial struggles and health struggles. They depend on Medicaid for medications and healthcare needs. It is a crucial part of their survival.

Jason Langford, Crockett, California

Dear Members of the Special Committee on Aging,

Community living matters to me because without I would be alone on the streets after my stroke

---

Carolyn Clark, Moreno Valley, California

Dear Members of the Special Committee on Aging,

Community living matters to me because

I work with kids with Autism as a behavioral technician and we need to be there these clients and others.

Mary Rodgers, Modesto, California

Dear Members of the Special Committee on Aging,

Community living matters to me because my adult son is disabled and on SSDI & Medicaid. He lives with me. I am an eldery woman, and I help him by providing a safe environment for him as well as much-needed emotional and practical support, and he helps me by assisting with chores and loving assistance as I am aging. We have a cooperative arrangement which upholds his stability and my stability. Without these services, he would not be able to afford his medications (severe mental illness) and help me with housing assistance. He does volunteer work half-time for the National Alliance on Mental Illness and this provides him with much purpose and a framework of structure where he assists others in their struggles with mental illnesses. He is saving lives by doing this work. Please do everything you can to prevent cuts in services as our very lives depend upon it. Thank you.

Melissa Fitch, Santa Barbara, California

Dear Members of the Special Committee on Aging,

My son is 23 years old he has Down Syndrome and Moyamoya - a rare arterial brain disease which he had 2 brain surgeries for in 2020. Without Medical we would of had to sell our house to have his health needs taken care of. Thanks to the amazing doctors and care he received he went on to go to a 4 year university inclusive program for students with intellectual disabilities. All of these things would not have been possible for him with out Medicaid funding. He is now done with college and is a thriving member of our community. He has a job, he volunteers in his spare time - at our hospital and hosting karaoke events for individuals with disabilities in our community. He has friends and a bright independent future ahead of him thanks to supports he receives. Without Medicaid HCBS he would be leading a very different life.

Joseph Gilbert, Ojai, California

Dear Members of the Special Committee on Aging,

Community living matters to me because we are social beings. We all flourish together.

Ron Parsons, South San Francisco, California

Dear Members of the Special Committee on Aging,

Community living matters to me because many of my friends are now older and need help.

Aidan Shanley, Walnut Creek, California

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps keep us united with many other people all wanting progress.

Ryan Duncanwood, Redding, California

Dear Members of the Special Committee on Aging,

Community living matters to me because

Eric is a warm and friendly young man who's a natural leader and makes people laugh constantly. His mother, Frances, worked hard to balance her roles as the primary earner for her family and parent of two children.

"His formal diagnosis is seizure disorder with cognitive delays, which took a long time for us to get from the time he was a baby," says Eric's mother, Frances. Eric's seizures started when he was just 11 months old; his lips would turn blue at night, and his parents can vividly remember seeing his tiny body on a full-sized gurney as the paramedics rolled him to the ambulance.

When Eric was 11 years old, he joined Kaleidoscope when it was an after-school program. Having aged out of day care, his parents needed a place for him to go. Frances remembers thinking, 'What do I do?' and started researching. She found Kaleidoscope, enrolled him, and he instantly made friends with the participants and staff.

In 2018, Kaleidoscope transitioned from an after-school program to an adult day health program for individuals 18 and up, with a focus on community integration. "This was such a blessing for us because Eric had hit the age where he no longer qualified for after-school services, so he rejoined the new Kaleidoscope program and is enjoying it every day," Frances says. The program plays to his strengths and gets him into the community to engage with others and try new activities.

Knowing that Easterseals Northern California provided a safe place for Eric to build skills and engage with the community granted Frances peace of mind and the ability to concentrate on advancing her career and maximizing her contributions. Frances spent 42 years driving technological development and innovation at a major American energy company. Advancement in her role required travel and extended hours, and the combination of Kaleidoscope and respite care made it possible for Frances to make these investments for herself and her employer.

Easterseals Northern California provided adult day services to 50 clients in 2024. Without these essential services, 50 adults with disabilities like Eric would need daytime caregivers. Many caregivers would be required to exit California's workforce, draining American companies of rare talent, exacerbating workforce shortages, and increasing reliance on costly social safety nets. Medicaid waiver services like adult day programs and respite care are efficient upstream solutions that boost our economy, enhance community engagement, and provide choices to families.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Colorado

Ekaterina Chernysheva, Englewood, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because

Stephanie Williams, Arvada, Colorado

Dear Members of the Special Committee on Aging,

I have been a recipient of HCBS services for over 15 years. In the beginning, these services helped my mother who was ill care for me. At the time, she had Parkinson's and would not have been able to care for me full time without essential HCBS services.

When my mom became too ill to care for me, I moved from Tennessee to Colorado because Colorado allows for more Home Care services and less institutionalization of people with disabilities. If Colorado and HCBS services had not been available to me, I would have been forced to enter a nursing home at the far-too-young age of 29.

Instead, after moving to Colorado and with the assistance of HCBS services, I became a disability advocate where I protested for disability civil rights, including the right to live in one's community regardless of disability status.

I also worked part-time as a disability advocate at an independent living center for people with disabilities for four and a half years. While there, I had the honor of attending the National Center on Independent Living Conference. This was only made possible through HCBS.

After leaving that job, I became a part-time consultant of sorts for a pilot program emphasizing the importance of community-based services and how important it is for these programs to be simpler to navigate.

After leaving part-time paid work, I then worked limited hours as a volunteer for hospice and for a Colorado organization which has a food delivery program for individuals who are homebound.

Without the help of home and community-based services, instead of doing disability advocacy, I potentially would have been stuck in bed with no way to even use the bathroom or get food. Alternatively, I could have been housed in a nursing home at the vital age of 29.

Even if I had not had the desire to work and volunteer part-time, I deserve to live as independently as possible. I can't imagine the detrimental physical effects of being trapped in bed

unable to get my most basic needs met, nor do I care to imagine the detrimental mental health effects of being housed in a nursing home before my 30s.

The best way for me to live my life is by living in the community I love and being around the people I love - my Colorado friends, wonderful CNAs, and amazing disability advocates. I would never have met any of these people if it weren't for HCBS services.

Don't make it harder to access vital HCBS services. Let people with a disabilities keep our Independence in our communities. It is our human right.

Tonja Weber, Colorado Springs, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because I have been a nursing assistant for almost twenty years working in hospice. My youngest son was not properly diagnosed until they were 18 years old with autism. I have always worked nights to care for my son during the day, and I am the only caregiver they have. Without Medicaid we would be homeless as we are already living paycheck to paycheck. My son could find no place to live on the $640 a month from disability if I was not here. Please keep our disabled citizens from suffering even more in these uncertain times.

Kinzie Acosta, Colorado Springs, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because my child deserves access to all resources due to her needs. She isn't an average child who can do things and she will be greatly impacted with the proposed changes. It's not fair to take from those who don't have access like the rest of us. The special needs should not be a target for cuts and loss of benefits.

Finneas Crystalite, Boulder, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because the Medicaid home and community-based services (HCBS) helped me to get into housing after years of homelessness and difficulty establishing support or connections anywhere that I tried to live, no matter what I tried or did.

As an autistic/ADHD adult without family or friends to rely on for support, I was struggling for years due to lack of proper resources or support, and it would have a horrible impact on my life if

these services and supports were not provided to me.

Without Medicaid home and community-based services (HCBS) I would not have housing for myself or my ESA. I would not have support in meeting my basic needs including housing, food, toiletries, support with transportation, support connecting in the community, and I would not be able to be a safe and comfortable member of our community.

Please continue to provide the Medicaid home and community-based services (HCBS). I rely on them for the ability to live a healthy and safe life.

I am certain that there are also countless other people who would also be homeless and unable to provide for their basic needs without these services and programs.

Thank you.

Amanda Sellen, Broomfield, Colorado

Dear Members of the Special Committee on Aging,

My husband and I are full-time caregivers to our two sons. Both of our boys have the same rare gene mutation. Even though our oldest is 14 and our youngest is 6, their cognition will never grow beyond that of a six-month-old child. We feed them, lift them, change them, comfort them, advocate for them. Every moment of their lives depends on us being fully present.

Medicaid HCBS isn't just a program for our family—it's the reason we can keep our boys safe. It's what allows us to stay home and care for them, to get them to every therapy, every specialist, every appointment they need just to maintain the fragile health they have. It's what lets us help them experience their communities in the small but meaningful ways they can.

Without these supports, I honestly don't know what would happen to them. Our ability to give them even the most basic level of dignity, comfort, and quality of life would be shattered. These programs are the difference between surviving and suffering for our boys. They deserve to be cared for, fully and lovingly—and HCBS is what makes that possible.

Kaleb Williams, Colorado Springs, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because
Colorado Medicaid benefits not only my life but greatly impacts its beneficiaries in my family.

Especially my three year old Daughter; who is disabled and has special needs that her parent CNA Mother tends to.

Community-based services such as permanent supportive housing (PSH)
Is designed to help someone like myself who has been diagnosed with Non Hodgykins Lymphoma and have been hospitalized on multiple occasions. To have an opportunity to live independently despite my disabling condition and below middle class income status.
(The department of local affairs - division of housing)
With supportive services and clinical care to assist individuals in obtaining and retaining stable housing.

The State Colorado's 1115 wavier allows Medicaid to cover housing interventions through a partnership with the Colorado Department of Local Affairs (DOLA).

And as it is to my understanding covered services began implementation with a phased approach beginning in July 1, 2025, Health First Colorado (Colorado's Medicaid program) can reimburse Supportive Housing Providers (PT 89/208)
for the following services:
•Targeted case management for housing support
•Pre-Tenancy Support & Tenancy Sustaining Services

Home and Communtiy-Based Services Waivers
An HCBS waiver is an extra set set of Health First Colorado (Colorado's Medicaid program) benefits that you could qualify for in certain cases.
These benefits can help you remain in your home and community. HCBS Waivers have extra program rules and some programs may waitlists.

What would happen to me personally if I didn't have the Health First Colorado Medicaid program would hinder and delay my future aspirations.
However a greater negative consequence the communities within Colorado as a whole without Health First (Colorado Medicaid) and Home and Community-Based Services Waivers.
These Government benefits stipend and uplift the economy, the community, and its children of which there are many.
As a Father I care about the future and independence of my child and the future of the families I see everyday.

Heather Wilson, Colorado Springs, Colorado

Community living matters to me because
We depend on these Services and yet Colorado is taking them away.

The DD Waiver cuts and reductions go directly against the Olmstead decision Colorado Choice Transitions and Bill HB25-1017.

Bill HB25-1017 is mentioned in the 2025 news articles. April 2025.

Please scroll down to where I have the *** as that is the information that I was originally looking for - moving adults with disabilities out of nursing homes and Intermediate Care Facilities and into homes within the community.

Google AI:
"Colorado Choice Transitions (CCT) is a program created to help people with physical disabilities move from institutional settings, like nursing homes, to community-based living to comply with the Olmstead v. L.C. Supreme Court decision. This landmark ruling determined that unjustified segregation of people with disabilities is a form of discrimination under the Americans with Disabilities Act (ADA), and states must provide community-based alternatives when possible. The CCT program provides services and support to facilitate these transitions. "
The other articles and information I'm adding are what I came across while looking for this information because I couldn't remember the name.
This is just some of the information that is out there that shows that Colorado has been moving away from placing people with disabilities into nursing homes and facilities and placing them into homes within the community.
The recent Medicaid cuts and upcoming changes are putting all of this at risk - people with disabilities will end up back in nursing homes and facilities when the state closed many of those down years ago.
The information is out there.

Brief history of people with developmental disabilities in Colorado
https://www.slideshare.net/slideshow/a-brief-history-of-services-for-people-with-developmental-disabilities-in-colorado-and-a-glimpse-at-the-future/9323639
1974/1975
https://atlantiscommunity.org/about-us/history-of-atlantis-adapt/

1999
https://archive.ada.gov/olmstead/olmstead_about.htm

*** 2013 plan ***
https://hcpf.colorado.gov/sites/hcpf/files/Colorado%20Community%20Living%20Plan-July%202014.pdf

*** Colorado Choice Transitions ***

https://disabilitylawco.org/sites/default/files/uploads/Fact%20Sheet_CCT.pdf

*** https://hcpf.colorado.gov/cct-manual ***
"The HCPF manual states:
The CCT program will complement the Elderly, Blind, and Disabled Waiver, Persons with Brain Injury Waiver, Community Mental Health Supports Waiver, Persons with Developmental Disabilities Wavier, and Supported Living Services Waiver. The populations that will be transitioned through the program include: elderly adults aged 65 years or older residing in Health First Colorado nursing facilities, adults aged 18-64 with physical disabilities residing in Health First Colorado nursing facilities, adults aged 18 and older with developmental disabilities residing in Intermediate Care Facilities (ICFs) and Health First Colorado nursing facilities, and adults 65 years and older and individuals under 22 residing in institutions for mental disease (IMDs)."
2020
https://coloradosun.com/2020/02/05/colorado-medicaid-waiver-disabilities/

March 2022
https://courthousenews.com/

2023 court case
https://coloradonewsline.com/2023/10/04/adults-disabilities-segregated-colorado-nursing-homes/

April 2025
https://www.denver7.com/news/politics/colorado-bill-aims-to-codify-supreme-court-protections-for-people-with-disabilities

November 2025
https://www.theindependencecenter.org/blog/olmstead-and-the-fight-for-true-community-integration/
This is what I sent for the public comment form that I'm being told doesn't count because people aren't paying attention to it.

As far as the Staffed Home Option - none of the families who have been providing care for their own children with IRSS have ever heard of or even seen this as an available option. I specifically requested extra help and staff in my own home for my own son starting in December 2025 until March 2026 with multiple IDT meetings with The Resource Exchange and was given a bandaid solution to use 2-3 days of respite care per month, 10 hrs behavior line staff per week and Supported Community Connector which has completely fallen through because we cannot find a competent provider for that service.
There's also the fact that my son is too severe and needs 1:1 and he does not qualify to be a part

of a day program, so that is not a part of his services either.

The Behavioral Line Staff is a horrible option that has nothing to do with behavioral intervention and is done without a BCBA or RBT and the fact that there's no access to true behavioral intervention with the DD Waiver is another area that is severely lacking.

The fact that the state wants to drastically cut pay rates to IRSS providers because of some made up staffed home rate is ridiculous. This option never came up once in our meetings where I requested extra help and Staff in my own home for my own son. The DD Waiver is supposed to be the most comprehensive waiver in Colorado and it has been severely lacking in what families need compared to the SLS Waiver. There needs to be respite care provided under the waiver at an hourly rate. Please explain to me this back up care that you mentioned because I do not have that available through the host home agency I contract through. They have never mentioned anyone caring for my son so that I can attend my own doctors appointments, etc. I can only use them for their respite care option that's 24 hour increments. My son needs the residential services because he's very at risk for being placed outside the home itself. I cannot just switch to a different waiver because the DD Waiver is becoming the Least comprehensive waiver available.

And, you have the fact that the respite my son receives us in homes that have 1-2 clients.

It has become all about the money these people earn to care for at risk individuals in their homes because their daily notes and logs are unprofessional and lacking. They also severely lack the training and knowledge to deal with behavioral issues.

The state moved to have people with disabilities living within the community instead of being placed in nursing homes and institutions and yet everything that is being done at the state level is putting this at risk population at risk for being placed in nursing homes and institutions again. It is completely backwards.

This PETI is ridiculous too.

My son only has SSI and after the money goes to room and board, there's only $170 left and it sounds like it goes to PETI.

S Host Home is not a nursing home and this PETI is really going to hurt people with disabilities who are already struggling financial.

The only people who are not struggling with the DD Waiver and Host Home IRSS services are those who have more than one client in the home or who also provide the Supported Community Connector themselves.

This option for me providing Supported Community Connector for my own son is different when he only wants to be someplace with me for 15 minutes at a time.

The fact that we cannot find an appropriate provider since Covid precautions lifted should be an indication of how severely disabled my son is and I cannot even get a level 6 SIS because I refuse to lie like other parents that I see whose adult children can do independent activities that my son is not capable of doing.

There are many things that have been and are still lacking regarding the DD Waiver and its services and I'm tired of my son not being able to get what he actually needs became he is physically healthy, yet he is still seriously developmentally delayed.

Please note that my son was always IDD.
He started Early Intervention at age 1 in Ohio.
He was diagnosed with Classic Autism and Speech and Developmental Delays at 21 months old in Ohio.
I was born and raised in Colorado Springs and lived in Ohio while I was married to my children's father.
My son had access to OT, PT, Speech therapy, and his Early Intervention Specialist was using ABA concepts with him.
He was in the school system from preschool on and receiving a Waiver in Ohio as well.
He received SSI before age 3.
This is just part of my son's journey and he is still seriously developmentally and intellectually disabled.
We moved back to Colorado in 2004.
He received the CES Waiver in 2008 and I became a CNA and family caregiver in October 2008 - right before the Family Caregiver Act became state wide in November 2008.
My son received the DD Waiver at age 18 in 2014, when the DD Waiver was for 21+ because his Case Manager fought for the emergency placement for him because we were looking to place him outside the home.
I became his Host Home Provider in October 2015 after we got everything transferred over for him.
My son was able to remain in the home, but he is at high risk for being placed outside the home.
I cannot just get him the SLS Waiver because the DD Waiver is severely lacking in services even now - other parents have mentioned this to me.
My son is at risk for being institutionalized because of these changes.

Please also note that providers, parents, and case managers have pushed people to get on the DD Waiver because of the wait-list instead of having people research which waiver would actually be the most appropriate for the person becoming an adult.
They obviously were very ignorant about how the wait-list actually works because there is the emergency placements that come up and it's not first come first serve.
I am sorry that this information is not put together better for you all to read.
I have copy and pasted some things that I have written previously.

This is Heather Wilson and I thank you for reading this about my son, Brian Thomas.
I am his guardian, advocate, Host Home Provider, and I will continue to do what I can in a single mother and single income household where I cannot even get a Day Program or SCC services for my son and having an outside job or even a 2nd job is and has always been impossible for me.
I cannot even get into the level of care issues that the SIS, ISLA and other tools don't help concerning my son because he can walk, but he cannot do anything on his own.

I help him with everything..
I cannot even get a level 6 SIS for him and you have people who can ski on their own with supervision who receive a higher SIS just because of seizures and their parents lying about things.
It has really been frustrating fighting for the services that we have and we cannot even access providers for SCC and Day Program.
I must go attend to my son and have had many interruptions.
I hope this makes sense to you.

Thank you for your time.

Pamela Clute, Colorado Springs, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because ,I believe that anyone with a child with disabilities should get all the help they need for their child, it's a full time job ,and there is no better person to take care of said child then their parent .

Brittny Tarango, Westminster, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows my son Jaxson to remain in my care and access services such as ABA therapy OT Speech Therapy. It provides services for him to gain access to the community and also helps with assistance in personal care tasks and other tasks where he struggles immensely unlike other normally developing 4 1/2 year olds. Community living allows Jaxson to work on his skills, such as socialization what is developmentally in behaviorally appropriate and learn to self regulate his emotions. Without His ces+ces services I fear Jaxson due to his behavioral problems will be institutionalized/ Jailed as an adult. Early intervention for him is crucial at this stage so that I can give him a fighting chance to be a functioning adult in a world that was not made for children like him. Choose our children their lives and futures depend on it!

Ashley Murray, Penrose, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because I have three boys with special needs. They require daily care and multiple therapies. Taking this away would be detrimental to their health and their

futures. Without the therapies and ABA they will not be able to learn the skills necessary for them to be productive members of society. I have also worked with disabled adults to help them find work and learn their jobs, this way they can be productive.

Christopher Grabar, Tulsa, Oklahoma

Dear Members of the Special Committee on Aging,

Community living matters to me because I want a safe place to live.

Thea Healey, Alamosa, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because it means my son and my sister can live at home with me, where they are surrounded by love, dignity, and safety. As their caregiver, I can make sure they have the support they need without losing the freedom and comfort of their own space — their home. They deserve a beautiful life filled with respect and compassion, and community living is what makes that possible. It keeps families together. It keeps hearts together.

Dawn Courtney, Fruita, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter wouldn't be getting out of the house and engaging with other people if it weren't for these programs. When covid came along, she stopped going out and then stopped wanting to go out. When we signed on with Respite Essentials, she blossomed and came out of her shell. This allows her to learn to engage with the community, work through the anxiety of going to new, unfamiliar places and being around other people, besides family. This program is crucial to her future and growth. She has done more new activities with community connector than she has with us, her parents. Cutting this program would be detrimental to her growth and her future to possibly learn to live in a group/host home or continue to engage with the community and her peers. Reconsider your position on this and how this will impact so many families who depend on the assistance and the needed respite from the continuous day to day struggles of raising a child/family member with different abilities.

Jane Kimsey, Las Animas, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because, I'm the mother of 2 special needs adults and it is nearly impossible to get the care they especially with having to fight to prove thry are disabled something that they have had since they were babies.

Rochelle B. Grand Junction, Colorado

Dear Members of the Special Committee on Aging,

11-20-2025

Dear Congressman Hurd,

I am reaching out to you to share my story and tell you what independent living in the community and services like HCBS have meant to me. As a person with a disability, the ability to have an independent life is a great source of pride and accomplishment and is often considered to be a great milestone in the life of a disabled person. Services and supports through HCBS means that a person with a disability can have access to things like a Personal Emergency Response or medic alert system to keep them safe and give them access to 911 when needed. These services can also provide assistance by offering and allowing for things like Medicaid transportation to get around in the community so that we can get to and from work, doctor appointments, grocery shopping, etc. depending on if needs are medical or non-medical in nature. As someone who is both a person with a disability and a disability advocate and social worker, I do understand the vital support that HCBS can provide those who receive it.
Living independently can allow a person with a disability to pursue their goals and dreams that they still want to accomplish in their life. It allows them the autonomy to make their own decisions by living independently. Something they don't have if they are living in a care facility. HCBS can also provide assistance with personal care or home services for those who are not under the new CFC program. Many individuals who might find it hard to keep up with cleaning of their home can find homemaker services beneficial to assist them with cleaning the house.

I know that personally I still have a lot of things I want to do with my life and a lot of goals that I want to see accomplished as a disabled person, but I can't accomplish those things if my freedom is taken from me to do it. If President Trump wants to put people back to work, which I think is a great thing, then he should allow us to maintain services under Medicaid that can allow us to live freely within our community so that we can live, work, and contribute to society and support our community in general. Don't close off Medicaid programs that can allow us to work in the community because you'll find that people with disabilities can be a very valued member of the workforce.

Medicaid Buy-in program for example allows individuals with disabilities to work so it doesn't

make sense to cut that funding if Trump wants to put people back to work. It's also hard for people with disabilities to find jobs now because the funding for Division of Vocational Rehab just got cut also as I was reading in the local paper just the other day. It's making it harder for people with disabilities to exist because of funding cuts to programs like DVR and others so we can't really afford to lose HCBS too. Special education funding also needs to be saved so that students with disabilities can have fair and equal access to education. Without an education, people with disabilities will also struggle to find jobs and won't be able to fulfill the work requirements set in place by the President so they can keep Medicaid benefits. It won't do any good to have work requirements in place if you cut all the funding that allows people with disabilities to work so they can keep Medicaid. How will those requirements be fulfilled if you cut off our ways to live freely and get around in the community so that we can work and live? I ask that Congress would seriously consider saving a lot of the funding related to people with disabilities because trying to exist without it is going to be beyond difficult. Thank you for your time Congressman.

Rodhe Banks, Parker, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because, Hi, as a parent of a non verbal, level 3 autistic son who isn't able to dress, bathe, eat, sleep bye himself, I can see him feeling shut in himself so to speak, as my heart breaks every day for him. As a parent caring for my son Patrick and advocating for our family daily I cannot make enough to support us and these programs make it possible, if he couldn't live at home he would very likely be misunderstood and institutionalized. His body would be alive but he would go downhill very quickly. These programs help him feel loved and helps him feel a sense of normalization within his community, being able to participate in empowering activities that increase his life skills and be out in the community. We are so grateful for these services because they make so so much difference in his quality of life, thank you

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Debra Kovacs, Aurora, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because my 42 year old son would probably be stuck in a nursing home or assisted living facility with elderly homebound people, and be unable to pursue his own interests. Such an inappropriate, inactive living environment would take a toll on his medical and emotional well being, depriving him of age-appropriate social interaction, work and volunteer activities, and most importantly life at home with his family.
We adopted our son as a toddler, promising him a loving forever family, not just a "fair weather"

source of tangible and emotional support that could be taken away by a government "care" system when the going got rough. It did get rough, with disabling complications from surgery at age three. Thanks to Home and Community Based Medicaid programs, our son remains in his family home, has been working a few hours a week for the past 25 years, and maintains friendships that have endured since childhood. This supportive program complements the "natural supports" provided by family and community with professional home health services, mentorship, homemaker services and non-medical transportation among other things, at a fraction of the cost of living in a more institutional setting. Thank you for your continued support of these valuable programs!

Donald Bruestle, Pueblo, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because all human life is sacred.

Ronald Brown, Longmont, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because my family and friends and neighbors are part of community living.

Dana Barela, Golden, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because everyone needs different kinds of help. People looking out & helping each other is why we are on this planet.

Kayan Sherrer, Evans, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because of I didn't have Medicaid I would not be able to afford going to the doctors. I need to go to specialist for my Lupus, my heart disease, and my Hashimoto disease. I would end up dead!!!

Constance Slaten, Cortez, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because at I had a son at 19 years old and he was so sweet and perfect. At 15 months he swallowed some poison that severely damaged his kidneys and cost him his hearing. Without help from SSI and Medicaid I don't believe he would have survived. His situation was later made worse due to schizophrenia. Luckily it was treatable. He eventually received a kidney transplant which
Saved his life. He is now 57 years old and able to enjoy a happy life due to community programs and home care.

Gabriela Antao, Eagle, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because disability justice is justice for all.

Belinda Lovins, Thornton, Colorado

Dear Members of the Special Committee on Aging,

We all deserve to live our life to the fullest with respect and dignity! Community living matters to me because we need each other! Enjoy the moment! We should not be sick or hungry!

Kelsey French, Colorado Springs, Colorado

Dear Members of the Special Committee on Aging,

Do you know what it's like to wonder how you are going to feed your child? Care for your child? Pay hospital bills on top of everything else? Get denied by insurance?

We do. Kaydence is a 7 year old girl who is living with Canavan Disease. Canavan Disease is a progressive neurological disorder that will eventually end her life. But Kaydence is so much more than her diagnosis. She is a little girl who loves music and her family. She may never be able to walk, talk or care for herself but the Medicaid waiver programs in our state of Colorado have been able to give her the best quality of life.

With the CHCBS waiver all of our daughter's medical expenses are covered. This includes equipment, doctors visits, therapies and medication. This has been a huge weight lifted off of my shoulders. Our social worker told us that she will be covered for life, which is drastically different from the state we previously lived in.

When we lived in Texas, I constantly stressed on how I was going to afford caring for my child when primary insurance wouldn't even cover the food she needed to survive. Or how was I supposed to work full time when an in home health nurse is hard to come by and unreliable. When we moved to Colorado, that stress just lifted off and I was able to focus on other things like giving her the best quality of life and making family memories together.

Colorado has also instituted the IHSS program in conjunction with the CHCBS waiver. This program allows me to be her paid parent caregiver which eliminates the need for the state to find us a nurse and for the sometimes unreliable schedules of those nurses. I can now have a reliable and livable income by providing care for my daughter. Allowing her a safe and comfortable life. This has been a blessing for us and we hope it continues to be so.
Please reconsider making cuts to the community living programs that enable children like Kaydence to have the best quality of life.

Casey Barrett, Westminster, Colorado

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter is 14 years old and completely dependent on me and my care for her. She is wheelchair-bound, she has a cortical visual impairment, hearing loss, a severe developmental delay, no fine motor skills, no head control, osteoporosis, sleep apnea, is oxygen dependent, etc. Basically functions as a one to three month old infant. She is incredibly sweet, the cutest, and her smile could melt Antarctica. The programs like HCBS are vital to her and myself. Being able to care for her not only provides a huge financial help, but also gives me an incredible peace of mind, because I know she's getting the proper care and comfort she needs. I do not have to guess or wonder who is doing or not doing a good job. She has eleven specialists that are in her care provider circle, and large monthly supply coverage, plus therapists and teachers. Her prognosis was 2 years. I firmly believe that she is 14 years old and thriving at her level because of the programs provided that have allowed me to give her the best care that I know how. She, and so many others deserve to be a part of the community. Everyone can teach us something, and gaining knowledge, understanding and new perspectives is vital to the growth of the human race.



Evan's Story – *Evan is a volunteer with the National Multiple Sclerosis Society. He is a sales professional with a Fortune Global 500 company and resides in Colorado with wife Margy.*

My wonderful wife, Margy, and I met 35 years ago in Denver. Margy was diagnosed with MS 29 years ago, just after we got engaged. Her journey started with a mild and typical form of Relapsing-Remitting MS. However, even after being on the most effective MS disease-modifying therapies available at the time, her MS progressed within about 10 years. She now lives with advanced stage Secondary Progressive MS and is completely disabled, requiring 24/7 assistance with activities of daily living, including: feeding, bathing, medication administration, bowel/urinary tract management, transfers, and more. The out-of-pocket costs for Margy's in-home care quickly spiraled to upwards of $70,000 per year – a major financial burden for us, which has forced us to sacrifice some of our retirement savings to get her the care she needs.

I never imagined having to play so many roles to keep my family going, including caregiver, spouse, parent and primary income earner. For the past 15 years, I have juggled the responsibilities of a career, putting our daughter Lauren through college, and providing and managing Margy's care. Through all these years, we felt alone—our commercial insurance did not pay for any of the chronic care expenses, and because I worked full-time we never imagined Medicaid would help us. Then, about three years ago, I learned about a Medicaid Home and Community-Based Waiver Program in Colorado designed for families like ours, with reasonable income and asset restrictions, which protects the caregiving spouse from financial ruin, and provides basic levels of support for in-home care.

After a long and exhausting process, Margy was finally approved for this program in the Fall. Now we are paying a monthly premium and receiving limited funding for in-home caregivers for four hours a day. While I am grateful to have Margy approved for the Medicaid waiver, and my financial stress has been reduced, our lives are still so tough. I can't even begin to describe how brutally challenging (physically, mentally, financially) chronic care management at this level has been.

When Margy wakes up each morning and smiles at the new day, I see a light shining in the darkness. That is what fuels me to come to Washington, to advocate for families who are struggling to survive and cannot fight for themselves. We must protect Medicaid funding.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Connecticut

Tere Hummel, Elmhurst Connecticut

Dear Members of the Special Committee on Aging,

Community living matters immensely to my son, Jason Hummel, because he needs to feel included and noticed by others for his accomplishments and for just being who he is. He attends a workshop were he feels he has contributed to society and it gives him a purpose and routine on Monday-Friday. Medicaid HCBS helps him by keeping doctor appointments, shopping for meal preparation, with transportation and his informed consent. Please do not reduce services for HCBS. People with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. HCBS help make this possible by helping people stay in their homes, work, and participate fully in their communities. Independence matters to him!

Lisa Considine, Trumbull, Connecticut

Dear Members of the Special Committee on Aging,

Community living matters to me because my son with disabilities has a human right to belong as a member our society. A lot of people with disabilities can be active members of the community given a chance. Isn't that a lot better than having to be a drain on the system. Medicaid him into oblivion it's not satisfying for them or the people around them. My guess is you're not gonna even read this letter anyway?

Kevin Walsh, Madison, Connecticut

Dear Members of the Special Committee on Aging,

Community living matters to me because My parents are getting old.

Gerolynn Laukevicz, New Milford, Connecticut

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps us all and to help those of us to help those in need. Getting involved and giving to your community helps pull it all together.

Karla Kelly, Vernon Rockville, Connecticut

Dear Members of the Special Committee on Aging,

Commmunmyity living matters to me because I have a son with disability that lives in a companion home for the last 15 yrs

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Brandon McGee, Newnan, Georgia

Dear Members of the Special Committee on Aging,

Community living matters to me because, our kiddo Isahiah, whom we adopted in 2020 at his age of 15, has Profound Autism and non verbal. He has the right to be in the community as a human being just like you and I. The HCBS helps humans like Isahiah and us the parents learn to live a somewhat normal life. In Isahiah's case he had had zero therapy when we adopted him. We came into this together no knowing what we didn't know about his severity and we started researching and making phone calls and was able to find an amazing BCBA that taught us how to teach him and how to handle behavioral situations. The school was a joke and did nothing for him. The community wasn't there for him the world around him wrote him off. I encourage you to keep HBCS for it is important in have an opportunity to have a life for these people.

Melisssa Meyer, Simsbury, Connecticut

Dear Members of the Special Committee on Aging,

Community living matters to me because solidarity

Clairence Pickens, Hartford, Connecticut

Dear Members of the Special Committee on Aging,

Community living matters to me because it's an essential part of my life and living therein ' So make no mistakes to what your obligations are to the community at large!!!

Carl Meyer, Simsbury, Connecticut

Dear Members of the Special Committee on Aging,

Community living matters to me because of self-sufficiency.

Cheryl McCann, Southington, Connecticut

Dear Members of the Special Committee on Aging,

Community living matters to me because
Community is necessary and helps to improve everyone's quality of life. In times of need or tragedy, communities come together, people help each other.

David Gephard, Centerbrook, Connecticut

Dear Members of the Special Committee on Aging,

Community living matters to me because if the Essex Housing Authority hadn't found me an apartment I would have been homeless. Almost all my neighbors where in a similar situation. I learned that others shared very similar as myself. We continually share with each other in ways to make Life easier.

If I didn't have Medicare or Medicaid, I would have no healthcare. My SNAP benefits allow me to fairly eat well. My S.S. does not cover all my rent, bills & food.

Jerry Rothman, Greenwich, Connecticut

Dear Members of the Special Committee on Aging,

Community living matters to me because my son, who is 27, is able to live a fulfilling life in a community where he is able to work part-time, go on trips, take classes and attend various events such as Special Olympics and social get-togethers. My son lives in a garden apartment complex in an apartment that is rented by his community, Judith Creed Horizons for Achieving Independence. He shares the apartment with a wonderful roommate, and they are able to access all that the community has to offer, such as a movie theater, library and supermarket, with staff support as needed. Without the Medicaid HCBS program, my son would have to continue living with us until we were no longer able to care for him. Programs like Medicaid HCBS are essential for individuals like my son in order to live fulfilling lives. Thank you.

Daniel Coogan, Columbia, Connecticut

Dear Members of the Special Committee on Aging,

Community living matters to me because of life

Hope Crescione, New Haven, Connecticut

Dear Members of the Special Committee on Aging,

Community living matters to me because I was a teacher for more than thirty years! I taught children who experienced a variety of disabilities at a private school where no special services were available. We worked with the families to learn about what accommodations were needed, and we made them. I also observed the children closely to further support their needs. Every one of those children added in a positive way to the group, AND were pleasures to have with us! I had no special training, except for also being a mom, and I NEVER felt burdened in any way. These children are now well into adulthood, and I'm sure they have continued to contribute over the years. EVERY PERSON HAS VALUE!

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Delaware

Amylynn Karnbach, Lewes, Delaware

Dear Members of the Special Committee on Aging,

Community living matters to me because i care about the well being of others! Folks are frightened about loss of food, income, health insurance, education, voting rights, housing, safety, security, medical care, reproductive rights, life partner choices, and loss of democracy !!!!!!!!!!!!

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61 Corporate Circle | New Castle, DE 19720-2439 USA
302.324.4444 | Toll Free 800.677.3800 | contact@esdel.org
www.de.easterseals.com

For Immediate Release
November 2025

For More Information
Verna Hensley (vhensley@esdel.org) or Natalie Scott (nscott@esdel.org)
302.324.4444

Easterseals Celebrates Family Caregivers All Year Long

New Castle, DE – "Dementia changes your whole life," Mary Gaffney, of Smyrna, says.

Mary and her husband, Donald, who have been married for 60 years, loved to travel. Unfortunately, Donald's dementia diagnosis brought those fun-filled adventures to a screeching halt. It was a hard adjustment for Mary, who was suddenly thrust into the role of full-time caregiver and quickly became overwhelmed. That is when her daughter found the Easterseals Adult Day program, and their lives became much brighter again.

"Easterseals has been excellent. I am glad it is available. Caregiving is a lot. Dementia is very disruptive," Mary says. "The atmosphere at Easterseals is great, and the staff has a great attitude. They really care for the participants."

Donald spends five days a week in the adult day program, where he enjoys arts and crafts, chair exercises, and singing. Recently, the program held a fair where participants enjoyed golfing, bowling, and other activities.

"Donald has peace there and is so excited to attend the program. They make him feel important. They keep the participants busy," Mary says. "When he is there, I run errands, go to my own checkups and care for my aunt. I also try and relax."

National Family Caregiver Month is celebrated in November each year; however, Easterseals Delaware & Maryland's Eastern Shore focuses on supporting families year-round. According to the National Alliance for Caregiving, there are more than 59 million unpaid family caregivers in the U.S. One of the greatest needs of these caregivers is information about services and programs in their community that may be helpful to them as a caregiver for children or adults with disabilities, chronic or terminal illness, or the elderly.

Like all Easterseals services, adult day services are comprehensive and individualized to meet each client's needs, family-focused to meet each family member's concerns, and goal-oriented to enhance independence. The adult day care program offers a break for family caregivers responsible for a relative who is unable to function independently but does not require 24-hour nursing care.

Through Easterseals Lifespan Respite Program, which provides funds to support family caregivers, Mary was able to take advantage of respite dollars to take a trip with family.

The Caregiver Resource Center and Lifespan Respite programs are partially funded by the Division of Services for Aging and Adults with Physical Disabilities through the National Family Caregiver Support Program, Title III-E of the Older Americans Act.

Easterseals Delaware & Maryland's Eastern Shore is leading the way to an inclusive community through its innovative services, which include: children's therapies, day programs for adults with physical or intellectual

disabilities, supported employment, senior services, recreational camping, respite services, and services for caregivers. To learn more about Easterseals, call 1-800-677-3800 or visit www.de.easterseals.com.



Donald enjoys being a part of the Easterseals Adult Day program, where he is engaged in activities daily.

# # #

U.S. SENATE SPECIAL COMMITTEE ON AGING

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DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from District of Columbia

James Driver, District of Columbia

Dear Members of the Special Committee on Aging,

Community living matters to me because it is important.

U.S. SENATE SPECIAL COMMITTEE ON AGING

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STATEMENTS FOR THE RECORD

Statements from Florida

Susan Swiden, Bradenton, Florida

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm a senior citizen with fibromyalgia. I was diagnosed in 2005. I lost my job, my apartment, my car and my 401K. I had to move in with my mother. I finally got Social Security after about two years. Receiving Medicaid saved me as it is doing now.
I live in Bradenton, Florida in a gated community. My father bought my mobile home for me about 9 years ago. This is a wonderful community with lots of amenities. I can't always participate but they are there for me.
If it wasn't for Medicare and Medicaid I'm not sure what I would be doing to survive. It pays for my prescriptions, doctors appointments and food. I know I couldn't afford my diabetes medications and all my other prescriptions. I would probably be living off one of my sisters.

Sincerely,
Susan Swiden

Donna Thompson, Dania Beach, Florida

Dear Members of the Special Committee on Aging,

I'm about to turn 75. I have a fracture of L4-5 and T9 and stay active. I have two PT jobs on my feet all the time.

I suddenly got my sciatic problem back. Excessive standing I imagine.

I am single do not own a house, pay rents.

Some day I'd like a 1/1 so I can get my belongings out of my 10 x 10 storage unit.

I can't afford the prices for rent so I've been a too late for the past 9 years.

I am eligible for both Medicare and Medicaid thank goodness.

So I am aging but I do take care of myself as best I can.

Thank you.

Donna T

Derek Manzella, Fort Lauderdale, Florida

Dear Members of the Special Committee on Aging,

Community living matters to me because it creates a sense of belonging and support. It allows people to share experiences, resources, and responsibilities, fostering cooperation and mutual respect. Living in a community helps build connections, reduces isolation, and encourages collective growth, making life richer and more meaningful for everyone involved.

Fonda James, Cocoa, Florida

Dear Members of the Special Committee on Aging,

Community living matters to me because I 'm a companion

Anne Bennett-Bready, Jupiter, Florida

Dear Members of the Special Committee on Aging,

Community living matters to me because my adult son with autism needs his group home. He has become very happy and and well and making progress living among his peers. My husband and I know that if we pass away tomorrow, he will be taken care of... please make sure these individuals have a secure future with their funding. It's piece of mind for parents like us!

Doreen Roethler, Leesburg, Florida

Dear Members of the Special Committee on Aging,

I am advocating for my 24 year old granddaughter who has a cerebral palsy diagnosis Her life is enriched by programs provided by Medicaid. She especially enjoys the socialization with other disabled people. Her family's budget is helped by being providing with some of the products and services she needs that makes her life easier and more enjoyable. If she did not have these benefits, there whole family would suffer the losses.

Toni Mascari-Luisi, Jupiter, Florida

Dear Members of the Special Committee on Aging,

Community living matters to me because my adult autistic son deserves to live with

independence, dignity and connection to his community. This would not be possible without the services that Medicaid HCBS provides.

Audrey Ashford, Miami, Florida

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a retired therapist and educator who has serviced so many via Medicaid. It is a lifeline , not a luxury. It is as essential as healthcare is to everyone. Inclusion and community living only helps people thrive and prosper. This is America and everyone deserves to do so. A. Ashford MA.

Nathaniel Ray, Micanopy, Florida

Dear Members of the Special Committee on Aging,

I am a home health RN who provides private duty services for a young man in a very rural community with an aging grandmother as his primary caregiver. The young man sustained a spinal cord injury in a car accident when he was 3 years old and lost his mother and sibling in the accident. His family situation is uncomfortable and difficult. Where he is currently forced to live on a dirt road in a small rural town in Florida he has very minimal accessibility to society. Medicaid home based care services such as private duty nursing improve his quality of life with not only hands on caregiving, but also companionship and a connection to the outside world. His grand mother's health is failing and there is no one else willing to step up to take care of him. Without private duty nursing community based care, he would be forced to move to a Medicaid nursing home where as a young adult would likely truly struggle with the environment. Community based care keeps him at home in a comfortable environment where he can work on getting his GED and try his best to learn how to find his place in society.

Rhonda Sherrer, Sumterville, Florida

Dear Members of the Special Committee on Aging,

Community living matters to me because our daughter is 46 and needs 100% full time care. She has Downs Syndrome and doesn't have capability to make decisions or cook for herself. B/c of community based housing I can work and take care of myself and husband when needed. We have to be out of town a lot and no family for her to stay with so the housing provided for her has impacted greatly her life and ours too. Life was difficult before she received APD and receives money for housing. Please keep this intact and vote for things to benefit our mentally needy in our communities. Thank you.

Isaiah Rivera, Lutz, Florida

Dear Members of the Special Committee on Aging,

Community living matters to me because as a 19yrs with living with Autism, Medicaid Home- and Community-Based Services (HCBS) allow me to remain safely in my home and maintain as much independence as possible. These services support me with daily activities that I cannot fully manage on my own due to my health needs, such as personal care, mobility assistance, and other essential tasks. HCBS also helps me stay stable, connected to my community, and able to focus on my health and recovery rather than worrying about how I will meet my basic needs.

Without HCBS, I would struggle to manage daily living activities safely and consistently. I would likely face significant health and safety risks at home, and I might eventually require hospitalization or placement in a nursing facility because I would not have the support needed to care for myself. Losing these services would also create emotional and financial stress, making it much harder to maintain my well-being and independence.

Isaiah J Rivera

Colleen Camp, The Villages, Florida

Dear Members of the Special Committee on Aging,

Community living matters to me because with much hard work members of the Villages have established a 44 unit assisted living facility for disabled adult adults living in the Tri-County area. We attended a meeting about it and my 39-year-old son was very excited about the possibility of living semi independently with more opportunities for socialization.

Kathleen Eisenhauer, Port Charlotte, Florida

Dear Members of the Special Committee on Aging,

Life is not fair, and never has been. But, to open your heart to the diversity of one's community, to encourage acceptance and community support for people w/a wide range of challenges is exactly what our community is need!!

Tashia Holland, Bradenton, Florida

Dear Members of the Special Committee on Aging,

Community living matters to me because it gives my son a choice to live at home versus a group home. My son would not thrive in a group home and honestly wouldn't survive. The HCBS was a prayer answered. My son is allowed to move his life the way he wanted to not the way others want him to. We all deserve a choice.

Andrew Puleo, Indialantic, Florida

Dear Members of the Special Committee on Aging,

My Community living matters to me because it offers affordability.
Please stop enabling:
1. the eviction of mobile home residents once their parks are sold
2. the rezoning of property from Mobile Home Park to Condo, residential or any other
3. Enabling the dissolution of existing Mobile Home Lease provisions such that market values for such existing lease property is not conveyed to current lessees, iow buy out at value the potential buyer speculating on

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Janice Andujar, Orlando, Florida

Dear Members of the Special Committee on Aging,

Community living matters to me because

Sherri Collar, Florida

Dear Members of the Special Committee on Aging,

Community living matters to me because Medicaid helps me because I became disabled. A quarter of getting Medicare and Medicaid helps more than Medicare without having to have co-pays or cash on hand which most times we don't, I don't make that money on disability so I can't afford much and being unsexate helps me pay my rent. Because I couldn't afford it. With the money that I make living in the community alone with my dog. I seldom get, but when I do. I try to help people in the community or donate money or food to the community.
And I tried to attend church as much as I can. But yes, I would probably die without Medicaid. It's all I have.

Irma Romero, St. Cloud, Florida

Dear Members of the Special Committee on Aging,

Community living matters to me because
I'm disabled and need surgery also a senior citizen who lives alone with service dog. I need help in my home after surgery so Medicaid is very important to me.

Heidi Breen, Port St. Lucie, Florida

Dear Members of the Special Committee on Aging,

It would be fantastic if since the cost of living and minimum wage were increased that the threshold for foodstamps be increased. Many of us make within $100 or so too much now to qualify for food stamps or food banks now and struggle to make it through 2 weeks let alone a month due to the drastic inflation over the last couple of years.
I know there are people that make much less than myself I feel for them at least they are getting different types of welfare assistance. Please don't take these services away they are essential to the disabled and elderly.

Jeannie Gauthier, Miami, Florida

Dear Members of the Special Committee on Aging,

Community living matters to me because my son would be completely alone in the world without his friends and support system.

Renae VanWagner, Lake Worth, Florida

Dear Members of the Special Committee on Aging,

Community living matters to me because it protects vulnerable communities

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Peter Bromer, North Miami Beach, Florida

Dear Members of the Special Committee on Aging,

Community living matters to me because we need to revive our government.

Gladys' Story – Easterseals South Florida



We're so grateful to see the positive changes that have taken place in our mom Gladys' life since she started attending the Easterseals South Florida Kendall Adult Day Care.

The support and love she receives from the caring and dedicated staff, as well as the interaction with fellow clients, have made a significant difference in her well-being.

Our mom's quality of life has improved exponentially during the time she's been at Easterseals. She wakes up every day looking forward to going, and she comes home full of stories about the amazing care she received and the activities she participated in. It fills us with such joy to see her so happy and engaged with life.

At the Kendall Adult Day Care, our mom has had the chance to take part in a variety of activities that have help her to stay active and mentally sharp. From reading to arts and crafts to gardening, there's always something fun and engaging for her to do. And the best part is that she's doing it all in the company of her peers and people who care about her and support her.

As her children, it's heartwarming to see the bonds our mom has formed with her fellow clients and caregivers. They've become like a second family to her, and we see first-hand that she has such a wonderful support system.

Overall, we're in awe of the exceptional care and support that our mom has received at Easterseals South Florida. The center has improved the quality of life for our entire family, and it gives us peace of mind to know that she's in such capable and loving hands and living her life to the fullest.

Mercedes' Story – Easterseals South Florida



My mother-in-law Mercedes turned 103 years young in May 2025. She is amazing, and I credit her longevity in most part to her long-term engagement with the Easterseals Memory Gym day care facility in Miami.

At 89, Mercedes was diagnosed with Alzheimer's disease that has increased to include Lewy Body Dementia over the last 11 years. I enrolled Mercedes in the program over 10 years ago to keep her mind active and to continue her habit of social activities. She was a pharmacist until 89 years old and the treasurer of the Cuban American Association in Exile for over 40 years. Her social life with professional colleagues and longtime friends circle was vast. She was always busy with luncheons and hosting continuous education events for pharmacists to upgrade their professional degree. She has outlived all her friends and business colleagues, so attending Easterseals Memory Gym, 3 days a week, keeps her active and engaged mentally and socially with new friends. It helps her stay on a routine, she sleeps better and is less anxious. Most of all she has fun and enjoys her time playing games (dominos is her favorite with the help of other clients and staff as her eyesight is compromised) and getting out of her house and recliner to enjoy time with friends and staff at Easterseals.

Easterseals has become family to Mercedes and to us. They celebrated her last three birthdays with a huge party, inviting and receiving proclamations from the Mayor of the City of Miami, Miami Dade County, the President of Easterseals South Florida and everyone

who attends and works at the Easterseals Memory Gym. It was a special event and party from a special, caring group.

I trust Easterseals staff and appreciate all the communication and updates they provide on a regular basis. They stay actively involved and are true partners to caretakers. My husband and I sleep better knowing she is in the best care and safe. I have never visited the center without seeing staff members (front desk, aids, social workers, physical therapists, directors, and leaders) actively involved in the care and nurturing of their "guests/clients". They are a client first/family first organization who has genuine empathy for the role of the caregiver and the toll it takes on families. They keep connected with us, to ensure we are whole, as they enrich Mercedes life with high care and engagement.

Quite frankly, Easterseals, Miami Memory Gym is one of the most important blessings we are grateful for in our lives. Our life would be so different, Mercedes' life would be so different---not nearly as stimulating and she would not be mentally and physically where she is today at 103, without the support, care and professionalism of Easterseals.

Myriam's Story – Easterseals South Florida



We sought out Easterseals South Florida when our mother began suffering from Alzheimer's disease.

I first learned about Easterseals and the vital services they offer to the vulnerable in our community when I was an associate at Holland & Knight.

I had the privilege of attending a luncheon fundraiser where I saw first-hand the positive impact of Easterseals at that time - not knowing that 20 years later, my mother would benefit from their services. Alzheimer's disease is extremely alienating.

Easterseals has combatted the loneliness often associated with this disease. It has given my mom a loving community and a place where she feels loved and cared for. Our 84-year-old father, husband to our mother for 50 years, is the primary caregiver for our mom. They live at home with family and are surrounded daily by their children and grandchildren. However, the busy pace of life creates a huge need for a loving space where our mom can be cared for while family members work and attend school.

Easterseals also provides a much-needed respite for our elderly father who also has medical challenges. Our mom started attending Easterseals in 2018. She loved dancing to cumbia from her native Colombia with her friends at the Easterseals.

The staff provided her such joy and moments of happiness at a time when she most needs it. Easterseals is like a second home to us.

Submitted Written Testimony From
Disability Rights Florida For
The Senate Special Committee On Aging Hearing On
Aging in Place: The Impact of Community during the Holidays
December 3rd, 2025

Chairman Scott, Ranking Member Gillibrand, and other members of the committee, thank you for convening this hearing on an issue that is critical to Floridians with disabilities and older adults. "Community" is where Floridians with disabilities want to live, access services, work, learn, and participate fully in all facets of society.

Since 1977, Disability Rights Florida has served as the Congressionally authorized Protection and Advocacy (P&A) system benefiting all Floridians with disabilities through the provision of legal and advocacy services as specified across relevant federal grants and programs.

Community inclusion is essential for Floridians with disabilities and older adults because:

- It reduces isolation which lowers the risk of abuse, neglect, and financial exploitation;
- It ensures access to tailored resources and services while promoting awareness of rights; and
- It fosters shared experiences, peer support, and a sense of belonging through inclusive activities that encourage engagement and participation.

Disability Rights Florida advocates for all aspects of community living: education, accessible housing, employment, and transportation, and ensures services are delivered in the most appropriate integrated setting. Disability Rights Florida collaborates with organizations such as Independent Living Centers, Developmental Disabilities Councils, University Centers for Excellence in Developmental Disabilities, and others to achieve a society where Floridians with disabilities are fully included and recognized as integral members of their communities.

Each year, Disability Rights Florida submits Program Performance Reports (PPRs) that demonstrate the impact of our work. While these reports are not standardized, they consistently show how Disability Rights Florida advances community integration for Floridians with disabilities.

For example, in 2024:

- Over 16,000 Floridians with disabilities received "appropriate community-based services or AT devices and services that promoted independence and

integration" through programs such as the Protection and Advocacy for Individuals with Developmental Disabilities (PADD), the Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI), Protection and Advocacy for Assistive Technology (PAAT), and Protection and Advocacy for Voter Access (PAVA) programs. Moreover, several Floridians with disabilities were also "able to remain in their own homes" through the work done in those programs.

- Under the Protection and Advocacy for Individual Rights (PAIR) program, 29% of clients served were aged 60 or older, and 79% of all PAIR clients lived in the community (independently, in a parent or family home, or in a community residential home living arrangement) rather than institutions.

Community inclusion is not just a goal; it is a right and a necessity. Disability Rights Florida is at the forefront of ensuring these rights are realized across all areas of life: education, employment, housing, transportation, healthcare, etc. We work every day to make sure that Floridians with disabilities and older adults can live with dignity, independence, and fully participate in society.

We appreciate the committee's attention to this issue and look forward to continuing our work together to build a society where inclusion is not just an aspiration, but a reality for all. Should you have any questions, please feel free to reach out to Tony DePalma, Disability Rights Florida's Policy Director, at tonyd@disabilityrightsflorida.org or via phone at (850) 488-9071 extension 9737.

Respectfully submitted,

Cherie Hall
Executive Director,
Disability Rights Florida

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Georgia

Monica Pierce, Smyrna, Georgia

Dear Members of the Special Committee on Aging,

Community living matters to me because7

Delicia Smith, Stone Mountain, Georgia

Dear Members of the Special Committee on Aging,

Community living matters to me because; I am a and have also been a person to service the community and others. Only because I've lived the life others are living. I'm a 38 year old Mother of 5 Blessings. I've been out of work for the past 3 years now. I'm injured and not able to really work. I have too many injuries. I'm under doctors care because of my injuries. I've been struggling all my Life. When I was able to work I had money to help others. Now I have nothing. Waiting on my social security taxes or something to give me financial relief while trying to heal. I know my Grammer my not be correct. I'm speaking for my whole Dekalb county area. I know we truly need help. I'm able to help you in return for helping me. Together we can offer knowledge and strength to rebuild communities properly. Also gain the people's trust.

Joan Griggs, Covington, Georgia

Dear Members of the Special Committee on Aging,

As a young man who was diagnosed with autism at age 3, Ryan has many abilities yet many inabilities. Had he not been living in the community these past 31 years, he would certainly have much less abilities. He would not benefit from a group setting due to his communication difficulties. To prosper, he needed one on one instruction and the opportunity to make his own decisions.
Due to the amount of therapy, individual interactions, community involvement and individual freedom, he has grown into a very smart and funny young man.
Had he grown up in a group setting, he would not be the individual he is today but someone totally dependent on others for every need.

Bill Hals, Atlanta, Georgia

Dear Members of the Special Committee on Aging,

Community living matters to me because, as a retired RN/MSN (Masters in Community Nursing) - I has seen many programs to assist, train, re-orient (Veterans. like my self {18 months

in Nam}).
So many that work with handicapped, mental, physical or mixed do so much good! These programs, run properly, create people who end up returning more good in occupation, citizenship then letting them become homeless or criminal!

Joyce Lewis, Lithonia, Georgia

Dear Members of the Special Committee on Aging,

Community living matters to me because my main community is a senior apartment complex. The majority of the residents receive SNAP and Medicaid. Our rent is partially assisted by an income-based HUD program. I don't know what would happen to this community is those benefits were taken away.

U.S. Senate Special Committee on Aging

"Aging in Place: The Impact of Community During the Holidays"

December 3, 2025

Statements for the Record

Statements from Hawaii

Meet Bennett and his mom, Katie!

Bennett's mom, Katie, brought him to Easterseals 25 years ago. Bennett joined Easterseals Hawaii's after school services when he was 13 years old, and today he is thriving as a participant in the Adult Day Health program. Katie attributes her ability to have a fulfilling 40-year career in the workforce to having a safe day program to care for Bennett during her working hours. She served her community as a financial advisor at a major bank and says that without Easterseals, she would not have been able to keep her job. Katie doesn't know how she and her children would have survived if day services didn't exist. Bennett reports that he enjoys working on his skills and going out in the community with his Easterseals team. Katie wants other families to have the same opportunities that hers had.

Easterseals Hawaii provided adult services to 218 clients in 2024. Without this essential service, 218 adults with disabilities would need daytime caregivers. Many caregivers would be required to exit Hawaii's workforce, exacerbating workforce shortages and increasing reliance on costly social safety nets. Medicaid waiver services like adult day programs are efficient upstream solutions that boost our economy, enhance community engagement, and provide choices to families.

Kirk Tanaka, Makawao, Hawaii

Dear Members of the Special Committee on Aging,

Community living matters to me because to be alone is not a beneficial way to live.

Karin Koga, Waimea, Hawaii

Dear Members of the Special Committee on Aging,

Community living matters to me because our adult son who has severe autism and OCD has benefited from home and community-based services that have taught his social and life skills. During the pandemic, our son was afraid to leave the home and was unable to care for himself, and was completely dependent on us, his parents. Now that he has regular home and community based services, he has gained the confidence and skills to be able to go to medical and dental appointments, grocery shop using his SNAP benefits, and cook and clean for himself. He has learned to have conversations with others and has developed better self care habits including hygiene and exercise. As aging parents, we depend on outside help to assist our son, and we see how important these relationships and structure are to him.

David Mangel, Keaau, Hawaii

Dear Members of the Special Committee on Aging,

Community living matters to me because we will all experience aging and face the many issues that come with it. Imagine it's you or a loved one needing assistance.

Suzette Holtzman, Kaunakakai, Hawaii

Dear Members of the Special Committee on Aging,

Community living matters to me because I see how important it is to have housing for the participants who live in our group home. Three of them used to be homeless which is not okay for people with IDD to live on the streets.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Idaho

Elizabeth McNeill, Boise, Idaho

Dear Members of the Special Committee on Aging,

Community living matters to me because my children live in this community. I live and work in this community. My friends and family do too. When one of us is having a difficult time, we look out for one another in ways that make our lives better, people happier, and life better.

Roberta Knauth, Bayview, Idaho

Dear Members of the Special Committee on Aging,

Community living matters to me because without it at 74 I would need to bring my 50 year old son with intellectual disabilities back home to live with me. That would be so hard for both of us as we have spent the last 30 years making him as independent as possible. The hard truth is, I won't always be here and i want him to have a happy, safe life in community with people he loves and can depend on once I'm gone. In my situation, I lease the home he and his roommates live in. They pay the rent to the landlord and I help oversee the care and keeping of the home. Medicaid provides 24/7 care with staffing through a private agency called Renewed Horizons. Without this service we could not manage. Other services for community based living we receive are in home occupational and physical therapy, community access programs for recreation and ongoing education. We have community case managers who help us find services we need and check in on staffing and living conditions for continued healthy environment.

My son, David has a life that is full and rich with friends and activities that makes such a difference in both of our lives. He has opportunities to volunteer and serve others and be a productive citizen. It certainly has not been easy in a system that says "NO" at almost every turn. It has been an uphill battle for our entire lives. If these community based services disappear the choice between an institution, nursing home or God knows what is pretty grim. Of course I would bring him home with me as long as I draw breath but what after I'm gone? Someone once asked me what was my ministry. I told them this...this is my ministry. For 50 years I have worked within the framework of a broken system that operates on the principle of waiting until the wheels fall off to fix or not fix the problem. Instead, why not look at ways to prevent the problems and set our loved ones up for success. Help us help our loved ones to stay in community and live happy, healthy lives.

Charles Morrison, Lewiston, Idaho

Dear Members of the Special Committee on Aging,

Community living matters to me because I feel that everyone deserves to be treated with respect.

The handicapped and people of color are underrepresented and this needs to change. We need to ensure that all Americans need to have equity in our communities.

U.S. SENATE SPECIAL COMMITTEE ON AGING

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STATEMENTS FOR THE RECORD

Statements from Illinois

Dawn Bedell, Chicago, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because we have a right to safer, affordable housing, and quality healthcare. Stigma and misinformation about disability suggests most who are diagnosed as disabled can't care for themselves or pose a threat to the norms of society. The disadvantages of poverty and both urban and rural myths is a culprit also. Many lose hope in treatment for disabilities due to it being inaccessible or for fear of being brainwashed by a medical system that treats people like guinea pigs. Those who have used resources and treatment to gain some independence such as finding housing, and maintaining medical regime can be what a community needs to prove false narratives wrong. It's important for not just those with disabilities to feel a part of their community but for everyone to feel they have just as much an opportunity as another with or without disability to live a healthy and safe life where they can thrive.

Daniel Manobianco, Chicago, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because I Enjoy Good People.

Russ Ziegler, Downers Grove, Illinois

Dear Members of the Special Committee on Aging,

ComPeople with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. HCBS help make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.munity living matters to me because

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Cathleen Hendrickson, Rockford, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a disabled parent and I depend on these services to keep getting medical care. Many disabled people of all ages from new born to elderly are in need of these services which have been threatened repeatedly by this president Trump and his administration in such a way that it's an insult to the progress that's been taking place in the lives of disabled people in the last few years, example disabled people just had gotten the rights to

make above minimum wage right before this president decided to start cutting needed services for disabled children and young adults in our local schools as well as cutting funding for physical therapy that some of us rely on. Medicaid and Medicare,snap, WIC, IEP's are just as important or more so to the disabled and aging communities than to regular healthy people who don't have any impairments. To cut these programs for us in need is the same as undoing all the progress that's been made in the last 50 years towards making all lives better. Please keep helping us make further progress towards easing the struggles of the physical and mentally disabled so we can experience all that life has to offer at our own speed which may not be the same as someone who has no setbacks.

Cheryl Kinsinger, Washington, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because my adult son is supported in the community by a CILA and thriving in his current host home environment.

Elizabeth Grimwade, Chicago, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because I was born with congenital heart defects and am disabled. Access to accessible housing, community and employment greatly improve an individual with disabilities quality of life.

Debra Philips, Broadview, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because I have worked with participants with disabilities for 18 plus years and also I have a grandson that is under the autism spectrum. HCBS are needed and essential in helping those to live, go to school and work.

Jimmy Zollo, Chicago, Illinois

My name is Jimmy Zollo, and I am the Co-Founder and CEO of Joe & Bella, an adaptive apparel company dedicated to helping older adults dress with dignity, independence, and comfort. Our mission is rooted not in theory, but in lived experience; specifically, my grandparents' journey alongside two extraordinary people: Joe and Bella.

My family spent nearly a decade caring for my grandparents, who lived with both physical and cognitive changes that impacted their independence. During the Covid lockdown, my grandmother was living in a memory care community, and her ability to dress independently came to an end. That experience ultimately led to the founding of our company.

It was also in that community where we met Joe and Bella, two residents of the community who quickly embraced my grandparents and, for years to come, became part of our extended family.

Like many families, we began with uncertainty. We were unsure if we were making the right choice, unsure about the transition, unsure about the future. But what we found was transformative. Their care community became far more than a facility; it became a lifeline. It offered our family peace of mind, ensured my grandparents' safety, and most importantly, it restored joy and connection in their daily lives.

We witnessed firsthand the profound impact that high-quality senior living communities can have. Caregivers treated every resident with dignity. Programs supported engagement and purpose. Environments were designed to allow older adults to thrive physically, emotionally, and socially. When my grandfather could no longer dress himself with ease, it was caregivers who helped him maintain his sense of self. When my grandmother's mobility declined, it was community staff who ensured she still felt confident, valued, and seen.

Those experiences changed us. They inspired the creation of Joe & Bella, named in Joe and Bella's honor, and led our family to dedicate ourselves to the wellbeing of older adults and to the caregivers who support them every day.

I submit this statement to underscore a simple truth: senior care communities are essential infrastructure for America's aging population. As more families face the realities of aging, we must ensure these communities are supported, funded, and strengthened. They provide not only care but dignity. Not only services, but humanity. And for families like mine, families who want their loved ones to be safe, comfortable, and cared for, they provide hope.

On behalf of Joe & Bella, my family, and the countless families across the country who depend on these communities, I urge Congress to continue investing in and prioritizing high-quality senior living and the workforce that makes it possible. Thank you for allowing me to share our story and for your commitment to America's older adults.

Jose Nunez, Broadview, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because individualism is a set up for loneliness and other illnesses.

Valerie Callozzo, Chicago, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because

I began mentoring a 12 year old boy in 2012; he lived in a "therapeutic" group home. I don't know how many people realize this but neither DCFS not it's contracted agencies provide the services that claim to; if they do it is to a minimum degree. That said, this child was linked to DCFS from birth. He was adopted by his birth mother's cousin. His birth mother was serving 2-4 years in Cook County jail for, among other charges, failing to provide sufficient safety for her 5 year old son; while my mentee's biological father was sentenced to 75 years in the state penitentiary for murdering my mentee's 5 year old biological half brother. He has a sister who is one day less than one year older than my mentee; who became my virtual grandson. In terms of family, this child has a biological grandmother, an adoptive grandfather who was the most caring and nurturing of anyone around this boy (and his sister). His adoptive mother had a husband for about one year when she adopted the two kids. She had another husband when the kids were about 4 and 5. She also gave birth to two sons within that same time frame.

DCFS became more involved when he was 3 and started showing signs of ADHD. Backing up, the adoptive mother disciplined this child daily by physically beating him; he was often sent to bed without eating dinner; he was repeatedly physically and emotionally abused as well as emotionally neglected. His diagnoses include mild+/- cognitive impairment, learning disability unspecified and untreated; a speech impediment; 40% bilateral earring loss, ill-corrected club feet, severe trauma, cPTSD. (At age 18 he was walking with another boy from the same group home when the other boy pulled out a knife and stabbed my young man more than 23 times; he went into cardiac arrest three times and was on a ventilator for five days. A woman heard crying for help, the paramedics arrived in time to perform CPR).

At age three his "mother" began admitting him to psychiatric hospitals for purported aggressive behavior; most times the child denied any such feelings or behavior, but she insisted she wasn't comfortable taking him home. This scenario occurred 3-4 times a year. Often, she then refused to take him home giving the same excuse that she didn't feel comfortable. It not unusual for him to spend months "living" in the mental health unit of a hospital. He's almost twenty-two now. His grandmother, (adoptive) grandfather have cut him out of their lives saying he's too rambunctious and he's in legal trouble (he has never hurt anyone). I am the only adult who cares for him and about him and has a role in is life- a multi role; grandmother, advocate, emotional and financial support.

I don't how he would be able to live without the existing social services as feeble and minimal as they are. I am 75 years old, living on social security. I give to him all I can. He recently said to me, "we're like the two musketeers until one of us dies." I worry day and night how he will get. Our government was born of and remains committed to the wealthy, landed white man. People

like this kid will not be housed, will not eat or receive medical care without the help of the people-the government. Thank You

---

Rhonda Payne, University Park, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because I have an adult disabled son who just recently moved into a CILA a few months ago. He has high support needs and caring for him and keeping up with his daily needs, activities and appointments became too much as we are aging. He deserves to be able to live and participate in the community as a young adult with dignity and respect. It has been our goal for him to be able to live independent of us before we get too old and/or pass away. This is an opportunity for him to grow, be around peers and have a team of people assist him with his needs and activities. This gives him a sense of pride and independence.

Paul Koza, Libertyville, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because
wife and I are 71 years old and parents of 2, 38 year old autistic non verbal men who attend adult day programs. Because they are non verbal and autistic, they need the outlet of organization provided adult day programs. They also have done amazingly well attending those programs 5 days per week while living in a group home with another 46 year old disabled, legally blind verbal man. They live in a home which I purchased but is staffed by a provider organization (Riverside Foundation)
The home located in a residential area near our community high school and they are transported by staff but also are part of the neighborhood.
Funding for their caregivers, transportation housing costs and food allows my wife and I to support our other 2 sons, their families and our 5 grandchildren along with our disabled sons like every other family in our community.
They need the support of the Federal government (the Medicaid Waiver) to live a successful life in the communities
Thank you
Paul & Maureen Koza

Joseph Naidnur, Peoria, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because I have worked with this community throughout my social work career. I've seen firsthand how important these programs are to our most vulnerable members of society, who desire to love with autonomy, dignity and respect. HCBS ensure that folks who desire to maintain their lives in our communities deserve to have this opportunity, as I know this is what most of us would choose if we were under the same circumstances. Please fight to save these programs!

Susan Mekus, East Moline, Illinois

Dear Members of the Special Committee on Aging,

My disabled daughter is 38 years old and was born with a chromosome abnormality. She is developmentally impaired and is not able to live by herself. She is in a group home with ARC that is paid for by Medicaid and her SSI. If she did not have these services, we would have to bring her home to live with us until such time as we could no longer do so. Then what?!

Please vote to ensure her services continue so that families like ours are able to have our loved ones live as independently as they can.

Gregory Walkington, Skokie, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because it allowed my daughter with Intellectual and Developmental Disabilities to live at home in the community she grew up in. Colette lives at home with her mother and father providing her support for the last 31 years. Colette knows all of her neighbors and participates in all kinds of community activities and has belonging in her community. Everyone knows Colette. If Colette didn't live with us at home she would be in a state institution. Colette needs assistance with all of her daily activities. She needs help to get out of bed in the morning. She needs assistance dressing and grooming. She needs assistance to cook and clean. She needs assistance in the community shopping, going for walks, etc. She is also very medically fragile and has had over 100 brain surgeries in her life. Despite this she loves being around people and socializing with them.

Being able to stay in the community that she knows and they know her gives Colette a wonderful quality of love. She is all about people and loves to be out and interacting with everyone. The cost form Colette's care would be close to $400,000 in an institution. The cost to keep her in her community is much much less. The cost to the state to keep her in her own community is closer to $25,000 per year. So living in the community for Colette is a win win situation for the state. It costs less and provides a much higher quality of life. She is happier, safer and living the life she

chooses.

This is why HCBS matters!

Cheri BushongStarcevich, Pekin, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because, I am a widow, I'm disabled, I don't drive, I rely heavily on my personal assistant. Without the support of everyone, who is in need of help and support. I would definitely hope that someone, who doesn't rely on these programs. Would never ever think of not supporting them. No matter what!

Zaheen Isnan, Palos Heights, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because I have 2 kids with special needs and a mom(75 years old). I have to go to work my mom can't take care of her self she needs help with everything. I go for work and one of home worker come and help her with everything in the morning.

Tina Agnitsch, West Frankfort, Illinois

Dear Members of the Special Committee on Aging,

I'm writing this because people with families. Disabilities cannot survive without assistance. I am one of them. I am a single parent raising a 5-year-old and without snap and medicaid I would not be able to make it. I also work. But with a rising cost of food and live only the.
Rich can survive and nobody cares about the people that can't afford to eat and feed their children with light bills being 3 times higher than they used to be like a $1200 light bill for one month. How is the people supposed to pay these bills and feed their families? If there's no help , this is the most unhuman thing you guys have ever done. Does nobody value human life anymore? ?? I don't understand what's wrong with this government who poison us and lie to us.\n All while using our taxes to pay their salaries. But yet here we all are in my family being one of them who can barely survive. Because of what you're turning this country into. I know COVID was released on purpose, and then you gave the poison vaccine to the people who would listen to you guys and say it was safe. And now we find out it's not. I will never get a vaccine again in my life. Because of all the poisons, you put in them. And I promise who's ever in Congress government now, when election time comes again, they will not be in there. I promise, because the american people will vote them out as they should, it's time for newer and younger people

who understand how it try to survive in a world where you've tripled. Everything property taxes food cost of living electric bills. I could go on and on, so I think you should all look to God. And\n Pray for our country because you guys are all taking it away from us. And you don't care if we starve or liv, as long as your pockets are getting full with our tax money.

Michelle Billich, Chicago, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because I am very disabled.

Elena Storino, Tinley Park, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because my son, Leo lives in a CILA. If he did not have the funding for his CILA, I would not be able to work.
I have 2 sons with special needs, one of them is Leo. My ex-husband was abusive to me throughout the entire marriage. If I had know that the United States had group homes for people with developmental disabilities, I would have gotten out of the marriage many years before. This would have helped me tremendously because I gave up my job and my only income when Leo was born. I divorced my ex, but had to live with him in order to care for both of our son. I had no money. I am from Italy and I had no support. I was diagnosed with over 12 illnesses during the time I was with my ex and our kids. The reason why I was diagnosed with so many problems is because Leo would not let me sleep. He has a sleep problem and I had to keep him quiet at night so the others could sleep. During the day, the abuse from my ex and the non-stop work from the caring of our sons was so great that it almost killed me.
I am now working full time with CTF Illinois, but I have a lot of issue that are impacting my quality of life. I could have had a much better paying job by now and my own home and money in the bank and a good car. I have none of those things right now and it is very stressful. I have been renting a bedroom in people's home since 2012. Every time the living situation in the homes changes, I have to move out and find another bedroom to rent. All of this has taken a toll on my health

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Regina Jones, Dolton, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because some of my neighbors and myself are disabled and elderly. We all try to look out for each other. I love my neighbors and not being able to continue

to live in my community would be devastating. However, we're just trying to make ends meet with some of us on fixed income. We thank God for the food pantry Free N' Indeed to get us by for the month. However, we need more assistance with housing, utilities, healthcare, taxes and food ! Please bring all of these things down and make it AFFORDABLE !

Lisa Roche, Worth, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because I am mother of a handicap child and a coach of Special Olympics of 36 handicap adults and now that I've had a multiple strokes I am now considered handicapped so this is very important to me in multiple reasons, these adults that have a special needs are very smart very patient and most important. They love very hard to everybody so for hearing people that say that they are not important is Ludacris you Congress should do everything that you could do to take care of these children. No matter what.

Lashawn Tate, Homewood, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter has many of her resources in her community because of Medicaid! Never in a million years did I ever think I would have a child/young adult now with disabilities! Having Medicaid has been a blessing to me and my family!

Andrea LeVasseur, Chicago, Illinois

Dear Members of the Special Committee on Aging,

Community living matters to me because it makes a huge difference to the people with disabilities and older adults in my community! Because of HCBS, our services keep folks active, independent, and connected to their communities.

U.S. Senate Special Committee on Aging

"Aging in Place: The Impact of Community During the Holidays"

December 3, 2025

Statements for the Record

Statements from Indiana

My mother -diabetic, on 10+ medications, still no letter from FSSA

My mother is an MDwise HIP member with diabetes, and she relies on more than ten medications. Despite the announcement of the termination of MDwise's HIP contract, **we still have not received an official letter from FSSA** explaining whether she is impacted.

I am connected with families across the state who report the same thing many have not been notified at all or have received letters for the wrong person leaving us all confused an in the dark.

My mother's doctor does not accept all the new MCE options. This means we may have to change her medications, get new authorizations, or find different providers. For someone with diabetes, this is dangerous. This is not a simple insurance switch; it is a disruption to her medical stability.

My aunt — lupus, removed from Medicaid, now facing $4,000/month medication costs

My aunt has lupus and depends on medication to survive. She was recently kicked off the program after FSSA claimed her household income was too high. Because of this, she is now forced to pay **over $4,000 per month** for life-sustaining medication until this can be resolved.

No Hoosier with a chronic autoimmune disease should ever be put in this position.

3. My 19-year-old niece — full-time college student, Impacted by MDWise Contract cancellation

My niece is 19, in college full-time, and on the **HIP.** In January, she will be uninsured while trying to manage school, work, and her health. Young adults should not be losing coverage in the middle of their education because of administrative instability.

These are not isolated mistakes this is a pattern.

Three members of my immediate family have experienced direct harm due to unstable transitions, unclear communication, and inconsistent determinations. In my professional work with families and providers across Indiana, I see these same failures happening everywhere.

Hoosiers deserve a Medicaid system that is stable, functional, and accountable. Right now, that is not what we have.

Thank you for listening and for considering the real-life impact these decisions are having on Indiana families.

Delores' Story – Easterseals Northeast Indiana

It seems no one was more excited about Delores' birthday party than Dawn, one of the seven women Delores lives with in Hanna House in Columbia City.

Dawn, who has introduced Delores as "my wonderful roommate," circulated at the Creative Learning Center (CLC) at Easterseals Northeast Indiana the day before the party, making sure everyone knew they were invited to attend on Saturday, March 23. She also enlisted volunteers to help her decorate the CLC Saturday morning.

At 1 p.m., the official start of the party, Dawn fretted. Only a few staff and some of her housemates were there.

"Look at this! This isn't a party!" Dawn complained to Hanna House Supervisor Katie LaRue.

"No matter how many people are here, we'll have a great time," LaRue said.

After all, this was certainly a birthday to celebrate. Delores was now 95, the oldest person currently served by the Easterseals Arc network.
Delores ranged from happy to almost giddy throughout the party. She kept watch in a guest-of-honor spotlight with a clear view of the building's main door. The minute anyone stepped in the door, she'd call out, "Come on in!"

Soon more of her housemates, some with their boyfriends, showed up. Friends who attend the CLC on weekdays with Delores also showed up to join the party. More staff members who have worked with Delores stopped in, too.

First one of her sisters, then the other, showed up to celebrate. Then came cousin after cousin.

"I think she is really happy there," her sister Ardean Ebert said, referring to Hanna House. "She talks about 'the kids' all the time."

"The kids," ages 23 to 68, are the women who live with her at Hanna House. The age gap doesn't stop them from loving her. Some of them call her "Mom."

Her warm and jovial disposition makes her popular among most people she encounters.

"She's just so kind," said LaRue, the house supervisor. "She's a joy to be around!"

"She's got the joy of the Lord, doesn't she?" observed a cousin, Kathy Blessing.

“Our father would be so surprised to see her now,” Ebert said.

Farm and Family

When Delores was a little girl during the Great Depression, people with disabilities didn’t have the help they do now. Ebert recalls that her parents enrolled Delores in school, but she was picked on by other kids there. Before long, they kept her at home.

The routine on the farm filled her days. Family, extended family and neighbors made a close, comforting network around her. She particularly loved the animals. She enjoyed seeing the new calves, the cattle, the pigs, the sheep, the dogs…

“And the barn cats. She loved her kitties,” said a niece, Denise Geiger.

She gets to indulge that fondness for animals at the Hanna House, where the residents have a cat named Beans.

“If it had four legs, she liked it,” said her other sister Mardell Rhodes.

She helped her father on the farm, shucking corn and hoeing the garden, Rhodes said. Delores continued living with her father after her mother died in 1980. She stayed there, continuing to help as she could, until her father died in 1991.

She lived with Rhodes for eight years after her father’s death, but when a spot opened in Hanna House, she moved in. Now, more than 20 years later, Hanna House remains a warm haven for her, made all the warmer by her affection for her housemates.

Thriving with Easterseals

Rhodes marveled at how well Delores gets around; she uses a walker, but still enjoys outings. She’s grateful, too, for her sister’s continued good cheer.

“That’s all Easterseals,” she said.

“She likes to go to the Learning Center to do the crafts and things. She likes to paint pictures,” Ebert said. “She has at times gone to the humane shelter; she always talks about petting the kittens.”

“She likes to interact with people and to see what other (people) are doing,” Ebert said.

Another favorite pastime is shopping. LaRue said Delores recently learned how to operate the motorized shopping carts at Walmart. She also enjoys going out to eat with her housemates and working on puzzles during visits to the library, LaRue said.

As the sisters reflected on Delores’ life, about 20 people from Hanna House and the CLC played some of their favorite music, danced and enjoyed pizza, snacks and cupcakes. Ten

or so relatives caught up with each other and celebrated with Delores. Meanwhile, the guest of honor dug into a decadent double dose of chocolate: a bowl of ice cream and her own, personal cake.

Precious Johnson, Indianapolis, Indiana

Dear Members of the Special Committee on Aging,

Community living matters to me because my twenty-three Autistic son receives Medicaid Waiver Services.
My son has a Easterseals Crossroads job coach, a IPMG case manager, a therapist and recreational therapist.
The Medicaid Waiver Services are necessary to assist and support my son with daily work duties at Community North Hospital, a licensed therapist, a job coach, CICOA Freedom Transportation program and his IPMG case manager. As of November 23rd my son has lived in his own apartment for two years.

Sherry Burden, Grandview, Indiana

Dear Members of the Special Committee on Aging,

Community living matters to me because
We need to come together help one another I liked to see more programs for people like and many other citizens with disabilities

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Kristina Faulds, Anderson, Indiana

Dear Members of the Special Committee on Aging,

Community living matters to me because I personally am a parent of an Amazing 30 year old son with Autism & multiple other disabilities. We depend on these services every week! He is learning how to become more independent in doing various necessary life skills out in our community & has even started working this last July! Non of this would have been possible without these services! As my husband and I age, it is a huge goal of ours to try to help our son become more independent! Taking these services away from people like him would be horrible! These disabled individuals deserve the right to become all they desire & deserve to be! They can & will be valuable citizens with just a little additional help to learn how! Thank you!

William Baggett, Indianapolis, Indiana

Dear Members of the Special Committee on Aging,

Community living matters to me because as a disabled person (learning disabled) at this time in Indianapolis there aren't any resources available to me. I can't drive, I'm too disabled to depend

on public transportation so, for me I'm stranded. Indianapolis is a large city and growing daily should have better resources for the disabled and I'm elderly also. I can't get around because my income is come from social security disability. Barely enough to survive on. I'm very lonely and isolated because there is no service for me.

Michele Combs, Knox, Indiana

Dear Members of the Special Committee on Aging,

Community living matters to me because I love interacting with people after having MS for 22 years. I go to church to fellowship with others and donate. I also like to know people who are around my grandchildren.

Summerstar Brewer, Evansville, Indiana

Dear Members of the Special Committee on Aging,

Community living matters to me because4 job skills

Gary Brown, Huntington, Indiana

Dear Members of the Special Committee on Aging,

Community living matters to me because there's no help for those who are in between jobs. My wife lost her job because they asked her to do something illegal. She tried to do another job but couldn't because of her disability and because of that she lost her chance at food stamps and unemployment. She used to be disabled and really should be still but she wants to work. We have the foster children, legal guardian of four an older disabled son. We adopted seven children and they are all raised. Now we are raising seven more. It was prophesied to us at church that God would fill our house and God did. Including a girl we took in at age 15 when her mother passed away. A total of 15 children. This didn't include the children we helped with their children. I personally believe that there should be more help but more consequences for people who abuse the system. Like selling food stamps, etc. My mother now lives with us because she can't enough help to live on her own.

Susan Smith-Beard, Noblesville, Indiana

Dear Members of the Special Committee on Aging,

Community living matters to me because it has made a huge positive impact for my nephew who has Muscular Dystrophy.

Anna Roberston, La Porte, Indiana

Dear Members of the Special Committee on Aging,

Community living matters to me because a nursing home would kill me. I have Lupus and Epilepsy and I have a low monocyte count which means I am immune compromised. Staying at home keeps me safe from getting the myriad of infections and viruses that circulate in a nursing home. I am also allergic to perfume, Febreze and any scented cleaning product and perfumes trigger my Epilepsy. Spending 20 minutes visiting a nursing home that is filled with perfumed cleaning sprays is enough to make me have seizures. When I used to visit my Grandmother at her nursing home I would have to wear a carbon filter face mask and stay for a short time. I survived well in my home, in a germ free and unscented environment, living in a nursing home would probably kill me within a month. I am grateful to stay out of one and stay in my home. If you cut off Medicare and SSD and forced me into a scented and germ filled nursing home I would die quickly.

Madison Whitler, Indiana

My name is Madison Whitler, and I am reaching out as a healthcare professional working directly with vulnerable Hoosiers who rely on the Indiana Medicaid Waiver program for essential daily care. I am writing regarding an urgent situation involving a woman in our community who has been unable to access appropriate services due to significant delays in her waiver approval.

This individual experienced a major stroke and now requires daily support with activities of daily living, mobility, medication reminders, and overall safety monitoring. She has been on the Medicaid Waiver waitlist since August, and despite being medically qualified, her case has still not been approved.

Because of this delay, she is currently living in a private residential home that cannot meet her care needs. She is experiencing clear indicators of neglect, including inadequate supervision, lack of assistance with daily tasks, and unsafe living conditions. Her health and safety are at risk every day she remains without appropriate services.

Due to the waiver delay, she now faces an impossible choice:

Remain in an unsafe environment where her needs are being neglected,

or

Pay out of pocket for home-based care that she cannot afford while waiting for the state to approve the services she urgently requires.

No medically vulnerable Indiana resident should be forced into such a position simply because of administrative delays.

I respectfully request your support in:

Reviewing the current processing delays related to Medicaid Waiver approvals,

And advocating for faster processing timelines for high-risk individuals with documented medical necessity.

The Indiana Medicaid Waiver system is essential for keeping vulnerable residents safe in their homes and communities. When delays occur, the consequences can be severe—as in this case, where a stroke patient is unable to access the personal care and supervision required to remain safe.

Thank you for your time and for your continued advocacy for Hoosiers in need.

Mary Dooley, Elkhart, Indiana

Dear Members of the Special Committee on Aging,

Community living matters to me because both my mother and my sister were spared being in lockdown facilities because of the opportunities provided due to the funding. My mother shared a house in a real neighborhood with an older lady. Mom had schizophrenia so she needed to have support. She needed someone to make sure she took her medicine and got to her Dr appointments. The older lady needed round the clock support in case she fell or needed medical help. There was someone there at all times but they didn't live in an institutional situation. They had a real house and nice yard. They were able to go to store or out to eat. They were able to get their hair done. They never missed a Dr appointment because there was someone there to keep track of them and get them there. If there wasn't funding for this mom would probably have been put in a lockdown mental facility and the other lady would have been wasting away, waiting to die in a nursing home. As for my sister, she has a psychotic break and was admitted to a lockdown facility for many months. When she stabilized she was transferred to a group home where she was able to still get the supervision, and therapy she still needed while she was able to become part of society again. While she was there she received help with getting her disability. Now she lives in her own apartment instead of becoming another homeless statistic.
So as you can see I firmly believe that these programs were instrumental in providing a quality of life for them that was much better than what they would have had without them.

Christina Trimnell, Indianapolis, Indiana

Dear Members of the Special Committee on Aging,

This is my story.

My name is Christina, and I am a resident of Perry Township in Indianapolis. I worked for the City of Indianapolis for 20 years until my disability, a form of Muscular Dystrophy, made it impossible for me to continue working. Since 2003, I have relied on Medicaid's Home and Community-Based Services (HCBS) waiver to live independently and remain integrated in my community.

Because of HCBS, I receive attendant care during the weekdays while my husband works. On evenings and weekends, he provides support. Without HCBS, my husband would be forced to leave his job to care for me full-time. This would push us below the poverty level and likely into homelessness. HCBS allows us to maintain financial stability, dignity, and the ability to participate fully in community life.

With the help of my aides, I am able to enjoy everyday freedoms—such as going out to restaurants with my husband. We are food enthusiasts, and dining out is one of the ways we connect with our community. These experiences are not luxuries; they are part of living a full life, exercising my civil rights, and being included as an equal member of society.

The Americans with Disabilities Act (ADA) guarantees that individuals with disabilities have the right to live and participate in the community without discrimination.

Research shows HCBS improves quality of life, reduces reliance on costly institutional care, and supports family caregivers by allowing them to remain in the workforce.

HCBS is not just a program—it is a lifeline. It ensures that people like me can live with dignity, independence, and inclusion. Reducing or eliminating these services would not only harm my health and well-being but also violate the principles of civil rights and community integration established under federal law.

Mendi Cooley, Westfield, Indiana

Dear Members of the Special Committee on Aging,

Community living matters to me because my son has an intellectual disability. He brings so

much to every aspect of the community he is part of and he will need support to live independently in his community. The home and community based services he utilizes through the waiver give him the opportunity to master skills we all need to live in our communities.

Terry Jordan, Indianapolis, Indiana

Dear Members of the Special Committee on Aging,

Community living matters to me because, My Adult Son Has Autism, Epilepsy, Mild CP, & Learning challenges. He is an amazing Human Being who thrives in a supportive Environment. Being able to get services in the Home, where a Therapist works with Him in the Community has enriched His life tremendously. We put in the work with Him for over 33 years, with the support of phenomenal therapists, & He is coming to a point, we will be looking for Housing with another person or two, and Support Staff. Without the services that are currently available, He would have never reached the stage He is now at. We will forever be grateful! We have goals for Him, that He is starting to get excited about, as we talk it up daily. He LOVES cats, and desires to take care of Cats at an animal shelter. We call it "Socializing" Cats, while expanding His Horizons.

I have been Disabled for several years and have benefitted from services that have kept me in my home, which I am extremely thankful for.

my Mother has Alzheimer's Disease, and My Father was able to keep her home with Him with the help of in home services, until two years ago, when she could no longer walk & He physically could not care for her any longer during the hours the homecare staff wasn't there. So, he had to place her in a home. Without these services, my Son wouldn't be able to talk, make decisions, control his behaviors, He wouldn't have hopes or dreams or a future. Because of these services, you can have a conversation with him, he would freeze rather than decide, he would have outbursts when not with direct family. The opportunity to be with different people in different environments would not gave happened without the programs made available to Him through Waiver services. These opportunities have helped him grow as a person.

For myself, HCBS has allowed me to stay home, have assistance that has prevented falls & injuries, kept me in a place of being kept part of Society instead of closeted away somewhere to shrivel up and die. We live at a time where Extended care facilities, are short staffed regularly, the turn over is constant due to burn out, because of poor staffing. Poor staffing, is a problem, I have no clue how we as a society can fix. But, I have no doubt, it can be done with the right incentives. Whenever Possible, I think people should always be able to stay in their own homes. Because of the one on one care, burnout is seldom an issue. When I worked the field years ago, I did both, Residential care and Home care. I loved both. But, not everyone is cut out for both. Some do better with one over the other and that's great. I love that HCBS gives people a choice to have what's best for each individual.

My point being, Direct Care Workers, Disability Service Providers, & all Organizations that

serve persons with Disabilities & the Elderly are essential parts of providing persons with a good quality of life. In home is best whenever possible.
Thank you!

Tawonia Taylor, Indianapolis, Indiana

Dear Members of the Special Committee on Aging,

Community living matters to me because it gives my son the freedom to be in his own home environment with his family and friends. And it also gives him the ability to be taught how to Rand live independently.

Kat Kingsley, Elkhart, Indiana

Dear Members of the Special Committee on Aging,

Since becoming disabled at 36, my world, along with the community I had built have collapsed. While on Medicaid I was able to schedule rides to appointments. I recently moved to private insurance due to concerns over funding cuts to Medicaid. Private insurance does not offer transportation assistance which has made scheduling and getting to appointments difficult.
I would love to be involved in my community, through volunteering or simply being able to attend community events. I'm not able to due to a lack of transportation. This has left me isolated for the past 4 years. I'm not able to see friends, make new friends or contribute to my community. Before becoming a wheelchair user I worked at an art center, attended game nights with friends and helped manage community events. I was contributing and felt fulfilled. My life now is a stark contrast to the full life I had when I could walk with ease.
Programs supporting disabled people must be funded. There is so much the disabled community can offer to our surrounding communities. Our experiences are unique and worthwhile to the greater good of all communities. We should not be hidden. Our differences must be embraced. Able bodied individuals are only temporarily able bodied. This truth must be held in the forefront of policy making involving the disabled community. Whether through age or accident we will all eventually find ourselves as members of the disabled community. For this reason, these programs must be funded and expanded.

Kristie Pate, Anderson, Indiana

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm deaf and I'm unable to work and people like need more programs I can't afford to buy a new cellphone because I don't get very much on my

disability and the connectivity program ended because you people in the government refused to funded it I don't know sign language I was never taught I'm 55 years old and people like need to be able to communicate I have inno caption call on my phone but that's not enough I keep telling people that I'm deaf and the only other way is through via text messages or emails but a lot of places refuse to honor my request for those types of communication . I need a new cellphone but like I said I can't afford to buy one I really wished you people would help instead of taking photo ops all the time and I wished you people would listen to your Constituents and help us thank you and God bless you all

---

Milena Lukic, Indianapolis, Indiana

Dear Members of the Special Committee on Aging,

Community living matters to me because one day either myself, my family, my friends, or my neighbors will potentially become disabled. As we age, anything can happen to us or events unbeknownst to us will potentially occur. Those living with disabilities currently deserve a life of dignity as well, above all else. It gives them a sense of purpose and an ability to help the community in a way that makes them feel seen and heard. Please find the humanity in your hearts by continuing programs like Medicaid HCBS.

Mindy Cameron, Carmel, Indiana

Dear Members of the Special Committee on Aging,

Community living matters to me because my 24-year-old son lives with Duchenne muscular dystrophy. The Health and Wellness waiver in the state of Indiana enabled him to get his college degree while living independently with professional caregivers provided by a combination of the waiver, Medicaid, and services provided by the state Vocational Rehabilitation Program. He is now starting a career as a writer and editor. His success would have been possible without HCBS services.
His father and I have also been able to maintain fulltime employment because we have HCBS for our son. Duchenne requires full-time care for all activities of daily living, and without help, one of us would have to quit our job to care for our son full-time. HCBS makes our entire life possible and we would be functionally, mentally, and emotionally lost without them.

Jake Klemann, Indianapolis, Indiana

Dear Members of the Special Committee on Aging,

Community living matters because here is why I think that the Medicaid home and the

community based services they offer like so many different Medicaid community based services programs and each of them are different that will definitely have a huge impact onto other peoples life's inside there own homes and also that would have a big effect there communities instead of the institutions I think that for the arc of Indiana for people have disabilities that do have Medicaid or don't have Medicaid now if they don't have all of the correct and specific documents it's small possibility chances that they may lose free access to there own critical services by leading them to a hard potential financial by the hardship and also a reduced for the quality for life

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Kenneth Cloud, North Manchester, Indiana

Dear Members of the Special Committee on Aging,

because I've had 15 open heart surgeries I've been disapiled since I was born I can't work because of it

---

Indiana's Medicaid Crisis: A One-Page Summary

Why It Matters — Systemic Failures, Structural Risks, and Human Impact
Prepared by: Coumba Kebe, MPH | Date: 11/19/2025

Indiana is in the midst of a deepening Medicaid crisis that is harming families, destabilizing providers, and eroding trust in state institutions. This is not the result of fraud, misuse, or "runaway spending." It is the predictable outcome of years of underinvestment, rushed policymaking, and inconsistent oversight by the Family and Social Services Administration (FSSA).

Across the state, families with medically fragile children, seniors, and adults with disabilities are losing essential supports due to abrupt service cuts, inconsistent decision-making, and administrative breakdowns. Providers report overwhelming confusion, contradictory guidance, billing errors, and a lack of accountability from the agencies and contractors responsible for managing care.

At the center of this instability is a series of high-risk decisions executed without adequate planning or transparency:

- **The Pathways transition** created confusion, inconsistent guidance, delayed authorizations, service reductions, and fragmented communication across Managed Care Entities (MCEs).
- **The sudden termination of MDwise**, affecting more than 300,000 Hoosiers, was announced without a transition plan, risk assessment, or communication strategy placing massive strain on families and providers.
- **Widespread hour cuts and unclear eligibility changes** have destabilized caregiving arrangements and caused families to lose income, leave jobs, or go without essential care.
- **Administrative failures at Maximus**, including delayed assessments, documentation errors, and incorrect denials, have blocked access to medically necessary services.
- **Area Agencies on Aging (AAAs)** are no longer involved in Level of Care assessments or the Pathways onboarding process, removing the clear, centralized entry point families previously relied on for guidance, support, and navigation through a complex Medicaid system.
- **MCEs lack understanding of Indiana's Medicaid programs**, resulting in widespread billing issues, incorrect denials, and delayed reimbursement for hospice agencies, nursing homes, home care providers, and waiver programs.

Collectively, these failures have destabilized Indiana's long-term services and supports ecosystem. Hospitals are absorbing preventable crises, nursing homes face increased financial pressure, providers are considering dropping Medicaid, and families are being forced into impossible decisions about work, caregiving, and safety.

This is not responsible governance. It is a preventable humanitarian crisis affecting children, seniors, families, caregivers, and the providers who keep Indiana's healthcare system functioning.

State legislators must demand full transparency from FSSA, including the release of all data used to justify current decisions, the risk assessments (if any) completed before major changes, and a clear plan outlining how the agency intends to stabilize the system and protect vulnerable Hoosiers.

Indiana's communities deserve clarity, honest communication, stability, and a Medicaid system built on accountability not chaos.



Nick's Story – Easterseals Northeast Indiana

When United Way of Whitley & Kosciusko Counties asked for a volunteer who loves reading, Nick was an obvious candidate.

Nick, who participates in Easterseals programs in Columbia City, enjoys reading, particularly books about automobiles. Just as important, Nick is unfailingly friendly and outgoing. And when there's something special he knows about – old tractors, for example – he enjoys explaining it to other people.

Stephanie Turner, who oversees day services at the Columbia City Easterseals office, and Michelle Gibson, a community living staff member, invited Nick to share his love of reading with some soon-to-be readers: a kindergarten class at Coesse Elementary. He was quick to accept.

United Way started its spring "Read United" program in April. Through that program, volunteers go to elementary schools, reading books to children in their classes.

United Way selects four books for each volunteer to read, then the classes get those books after the readings.

Nick said he enjoyed asking kids questions after he reads and hearing what the kindergartners have to say.

"I asked the kids what their favorite pet is. I asked the kids, 'What pet do you have that you love?' One kid said, 'I have a gerbil that I love,' " Nick said.

"Nick has been quite the delight and we are very thankful for his time and service to our kindergarten group," said Lindy Cox, the office manager at Coesse Elementary. "If he would like to do this again next year, he is welcome to."

Gibson, the Easterseals staff member who took Nick to his readings at Coesse Elementary, said the children were quite absorbed in his reading.

"They were very quiet and attentive," Gibson said.

Nick began reading in mid-April and finished his readings early in May. After another of his readings, he asked the kids about colors they like.

"I asked them, 'what's your favorite color to color pictures with?' One of the kids said, 'I like to color with the color red.' Another one said, 'I like all the colors.' The colors of the rainbow! So, he colors with every single color," Nick said.

“Another kid told me he likes to read just like I do,” he said.

Expanding Employment



Zach joined Refreshed Tech in March 2024 and quickly became a valued part-time member of the cleaning team, responsible for preparing refurbished laptops, tablets, and phones for repair. With over a decade of experience in fast food, Zach brought strong attendance and punctuality to his new role.

His work involves a detailed checklist to ensure devices are thoroughly cleaned and ready for the next stage. Supported by an Easterseals employment specialist, Zach found a role that suits his love of routine and technology. He thrives in the structured environment, enjoys listening to music while working, and has even purchased a refurbished phone through the company's employee benefit program.

Elevating Community

Aubrie exemplifies community involvement through her many interests and activities. Participation in ES Gaming's esports team helped her develop confidence and learn leadership skills. Now she serves as president of the Client Council at Easterseals in Angola, leading meetings with empathy, encouraging respectful conversations and problem-solving. She also collaborates with Aktion Club on service projects, and she is a vocal advocate for herself and others with disabilities. Aubrie volunteers in the community, delivering meals and supporting blood drives, and performs in local talent shows.



Easterseals staff support her in living her best life, but Aubrie leads the way. She ensures the voices of people with disabilities are heard, respected, and empowered in her community.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Iowa

Evan Schultz, Des Moines, Iowa

Dear Members of the Special Committee on Aging,

I have a spinal cord injury and am paralyzed from the chest down.

Community living matters to me because I am able to live independently. I live in an apartment by myself only because of home healthcare. I received services from my home health agency, and home health aides assist me With Using the restroom, Showering, getting dressed and getting in my wheelchair for the day. They also assist me in meal preparation and keeping my home tidy.

I am able to work because of community living and access my community to enjoy events and outings. Without community living services, I don't know what I would do.

Garret Frey, Cedar Rapids, Iowa

Dear Members of the Special Committee on Aging,

Community living matters to me because I believe in the Olmstead Act, the ADA, Section II and that people with disabilities, elderly, veterans, and children and families deserve the services and supports they deserve and need w/o denials.

Mary Downing, Des Moines, Iowa

Dear Members of the Special Committee on Aging,

Community living matters to me because my baby sister has needed help

---

Jeanne Clapsaddle-Janssen, Cedar Falls, Iowa

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows my husband and me to work without worries. We have a 26 year girl, at home, with multiple medical issues and having nursing care gives us reassurance that she will be taken care in the comfort and safety of our home.

Michael Avery, Ames, Iowa

Dear Members of the Special Committee on Aging,

I am writing to ask for your support for Medicaid Home and Community Bases Services (HCBS) My son is a 35 year old diagnosed as being on the autism spectrum with an IQ of below 30. He has a limited ability to understand speech and will never be able to work.

Since 2019, he has lived in a group home supported by Medicaid HCBS. This has been a godsend for us as well as a huge positive for him. The love and caring he receives has enriched his life immensely. Losing this support would be devastating to him. He would also have to be sent to a nursing home with a cost to the government far exceeding what HCBS costs.

In addition, my wife and I are in our late 70's and cannot provide the 24/7 care and supervision he requires to say nothing about his continued care after our passing.

We urge you to fully support HCBS services through Medicaid. Our son's future support and happiness depends on you.

Evelyn Noel, Onslow, Iowa

Dear Members of the Special Committee on Aging,

Community living matters to me because my son who is Autistic & mentally challenged gets to do things & go places with the group. . Medicaid has helped keep him healthy & nursed him back to health when he had COVID. He might not have survived if not for Medicaid, he lost 35 pounds. Keeping him busy bowling, dancing, going for a boat ride. keeping him busy keeps him out of trouble.

Sharon Moss, Iowa City, Iowa

Dear Members of the Special Committee on Aging,

Community living matters to me because anyone can be injured or get a disease that leaves them disabled. This is especially true with the massive healthcare cuts starting next year, leaving Americans without treatment for preventable illnesses or adequate care for injuries. Older Americans are at greater risk of disability and we all get older. Prolife has to apply to human beings in one of the richest countries in the world.

Mary Doubrava, Urbandale, Iowa

Dear Members of the Special Committee on Aging,

Community living matters to me because every life matters

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Kansas

KEY MANAGEMENT

Bicentennial Manor Service Coordinator <bicentennialsc@keymgmtsites.com>

Fwd: Honorable Members of the Special Committee on Aging
1 message

leona Barnhart <barnangel58@gmail.com> Wed, Dec 3, 2025 at 9:55 AM
To: "bicentennialsc@keymgmtsites.com" <bicentennialsc@keymgmtsites.com>

---------- Forwarded message ---------
From: **leona Barnhart** <barnangel58@gmail.com>
Date: Tue, Dec 2, 2025 at 3:45 PM
Subject: Honorable Members of the Special Committee on Aging
To: leona Barnhart <barnangel58@gmail.com>

Leona Nelson

1010 W. 8th St. Apt 109

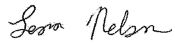
Junction City KS 66441

The Honorable Members of the Special Committee on Aging United States Senate Washington, D.C. Dear Members of the Committee,

I am writing to emphasize the vital role of community living in ensuring dignity, independence, and well-being for older adults and people with disabilities. Community living is not simply about housing—it is about belonging, safety, and agency. For older adults and individuals with disabilities, the ability to remain integrated in their communities means access to supportive networks, healthcare, and opportunities for meaningful participation. It protects against isolation, reduces unnecessary institutionalization, and affirms the right to live with dignity. I know this truth personally. Living in my HUD-assisted senior building has given me sanctuary during times of civic uncertainty and health challenges. My apartment is more than four walls—it is a place where I can protect my boundaries, recover in peace, and remain connected to my daughter, who is my anchor. My wheelchair is central to this independence. It allows me to move freely through my community, to access services, and to maintain my daily rhythms with dignity. Yet even with these supports, life on Supplemental Security Income (SSI) makes it nearly impossible to afford my basic needs. SSI provides only the bare minimum, leaving little room for medical supplies, transportation, or the rising costs of food and housing. Without community-based housing and services, I would face the risk of being forced into institutional care simply because I cannot afford to live independently. Community living ensures that limited income does not mean losing freedom, dignity, or safety. Research consistently shows that community-based supports improve health outcomes, lower costs compared to institutional care, and strengthen civic life. Programs such as home- and community-based services (HCBS) allow individuals to receive care in familiar environments, surrounded by family and neighbors, while maintaining autonomy. The Committee's leadership is essential in advancing policies that: - Expand funding for HCBS and affordable housing initiatives. - Protect the rights of older adults and people with disabilities to choose community living over institutionalization. - Support caregivers and direct service workers who make community living possible. - Ensure accountability for housing providers and local agencies to uphold safety and accessibility standards. - Strengthen SSI and related supports so that older adults and people with disabilities can afford their basic needs while living in the community. Community living is not a privilege—it is a cornerstone of aging with dignity and living with disability in freedom. By strengthening these supports, Congress can honor the values of independence, inclusion, and respect that define our nation. Thank you for your commitment to these issues. I urge you to continue prioritizing community living as a fundamental right and necessity for older adults and people with disabilities.

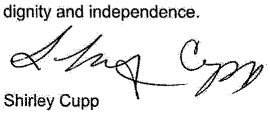
Respectfully,

Leona Nelson



December 4, 2025

I am writing this in support of Medicaid and HCBS funding. I rely daily on the support I receive through the HCBS FE-Waiver in Kansas. I am visually impaired and cannot ambulate without great difficulty, therefore, I am in a power chair, which was covered by Medicare and HCBS/Medicaid. Without this chair, I would not be able to live as independently as possible in my home. I would be receiving care in a nursing home. My aid helps in many day to day activities that I am no longer capable of doing . She runs errands for me and goes shopping, helps with bathing, housekeeping and laundry. She also assists with reading my mail to me. The HCBS services also provide my pull ups and transportation to non emergency medical appointments and telehealth, so I can be monitored more closely by my doctor and nurses. Nurses come to my home when needed to monitor me when needed. I have no immediate family that lives in the area, so I rely heavily on the services the HCBS waiver provides so I can age in place. HCBS/Medicaid is a necessity in my life as in many others so I/we can age in place with dignity and independence.



Shirley Cupp
1010 W. 8th Street
Junction City, KS 66441

My name is Patricia Joan Morgan and I am 78 yrs old and disabled. I have a home care worker who comes to my home and cleans my kitchen, bathroom, changes my sheets and vaccuums. She also does my laundry. I am unable to be on my feet or walk long distances, I need these services to be able to live independently.

Patricia Joan Morgan
12-3-2025

https://mail.google.com/mail/u/0/?ik=3dbbcb7006&view=pt&search=all&permmsgid=[illegible]

I do not know if I cannot live
here on my own without my
caregiver, because she
helps me with the things
that I cannot do on my
own anymore like cooking,
cleaning, she makes sure
that I don't fall because I am
considered as a fall risk.
and she gets my meds
ready for me every week.
and she does my laundry
taking me to my Doctors
appointments because I do not
drive, she checks on me if
I stop breathing at night.
She does my grocery shopping
if I didn't have her I would
not be able to be by myself
and I wouldn't be able to
afford a nursing home.
also I am using a cane and
a walker when needed.
Theresa Harrell
Tuesday December 2, 2025

Arlys Deckert, North Newton, Kansas

Dear Members of the Special Committee on Aging,

Community living matters to me because my son is on disability. He barely makes it financially even tho he has his own home. if I didn't help him out now and then I don't know what he would do. He has constant pain plus other physical issues.

Carolyn Hare, Leavenworth, Kansas

Dear Members of the Special Committee on Aging,

Community living matters to me because I appreciate we experience the joy of living and working together for the benefit of everyone.

Lisa Barcus, Lawrence, Kansas

Dear Congressional Committee,

Friends and family can't live without paying bills. People with IDD (Intellectual and Developmental Disabilities) who receive HCBS (Home and Community Based Services) can't live without paying bills, either. Kansas providers such Cottonwood, would not be able to pay people or provide services to people with IDD without HCBS services funding.
I live independently with the support of HCBS services every day. I work and get paid for two jobs. I have lived independently with support for 23 plus years. Without HCBS, I would be in pain and possibly not be able to live on my own.
I am asking you to not cut funding for HCBS services.

Respectfully,
Lisa Barcus, Self-Advocate
Kansas registered voter!

Kris Ehling, Wichita, Kansas

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows my family to continue to care for our adult disabled son. HCBS dollars allow us to hire direct service workers and respite care workers.

If we did not have HCBS as he was growing, our family would not have made it through the stress of raising him. As it was I was diagnosed with PTSD from the stress response to raising

him. While much better as an adult, he continues to need the supports that HCBS provides. In addition, I, too, benefit from those supports as I remain one of his primary caregivers.

HCBS has allowed us to access multiple life saving crisis and on-going mental health services. This includes regular therapy, occupational therapy, EMDR, psychiatric services, our local crisis center, law enforcement, and acute psychiatric hospitalization.

Please protect HCBS from cuts. Cutting this vital service would re-institutionalize the many people who have benefited from community living. Government continues to be the only organization that can operate "at scale" to protect the vulnerable. Cutting these services would be cruel, would demonstrate an unbelievable level of ignorance or even worse, indifference.

Please protect HCBS and Medicaid funding.

Kris Ehling, Wichita, Kansas

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows my family to continue to care for our adult disabled son. HCBS dollars allow us to hire direct service workers and respite care workers.

If we did not have HCBS as he was growing, our family would not have made it through the stress of raising him. As it was I was diagnosed with PTSD from the stress response to raising him. While much better as an adult, he continues to need the supports that HCBS provides. In addition, I, too, benefit from those supports as I remain one of his primary caregivers.

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Please protect HCBS and Medicaid funding.

Jessica Muckey, Wichita, Kansas

Dear Members of the Special Committee on Aging,

Community living matters to me because no matter how far gone these people feel that they are when they come to these places when they come in these communities, they realize and see that they are cared for. They are loved in ways that they have never been before. They have connection that they have never known before. They connected to resources that help them throughout their lives. Sometimes these places are the difference between life and death.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Kentucky

Nicolae Holley, Bowling Green, Kentucky

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows me to stay home to be a caretaker for my disabled mother and sister, rather than having to get a job and pay for a stranger to care for them or put my mom in a home.

Julie Broyles, Louisville, Kentucky

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm an aging senior parent of a 40 year old daughter as a resident with the cedar lake foundation. The funds needed to support both adults and children and their families are vital.

Julie Broyles, Louisville, Kentucky

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm an aging senior parent of a 40 year old daughter as a resident with the cedar lake foundation. The funds needed to support both adults and children and their families are vital.

Anetta Ali, Pleasure Ridge, Kentucky

Dear Members of the Special Committee on Aging,

Community living matters to me because I have 2 disabled kids who will become adults. And yes we work hard to make sure they get the skills and knowledge they will need. But for some kids and adults that will not be enough and they will need and do need the extra support. It means everything to the disabled people and their families that they have the resources to live as independently as possible with dignity and respect.

U.S. SENATE SPECIAL COMMITTEE ON AGING

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STATEMENTS FOR THE RECORD

Statements from Louisiana

David Bailey, Baton Rouge, Louisiana

Dear Members of the Special Committee on Aging,

Community living matters to me because I love people

Roland Thomas, Harvey, Louisiana

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps so many people

---

Christy Paulsell, Covington, Louisianna

Dear Members of the Special Committee on Aging,

Community living matters to me because my 40 year old daughter has survived SAFE and SECURE at HOME with the help of 7 caregivers through her Medicaid Home Community Based Service waiver after a near fatal motorcycle accident 20 years ago! Read our story/ BLOG on VisitTheNothshore.com .
Christy&PJ Paulsell
Covington, LA
P.S. an "institution" will kill her PLUS none available for for diagnosis of Traumatic Brain Injury with Quadriparesis and PEG feed!

Bonnie LeBlanc, Kenner, Louisianna

Dear Members of the Special Committee on Aging,

Community living matters to me because it makes me feel included in my community. I actually feel as if someone cares about me.

Mary Horn, New Orleans, Louisiana

Dear Members of the Special Committee on Aging,

Community living matters to me becausehelp

Natasha Laurent, New Orleans, Louisiana

Dear Members of the Special Committee on Aging,

My brother, Troy Laurent, is 42 years old and has Down Syndrome. Troy has been living at a group home through Magnolia Community Services for the past ten years, since 2015. His move to Magnolia was a positive, life-changing experience. Up till that point, he had been living with our parents, who are now in their late 80s.

Our family first became acquainted with Magnolia when Troy became involved in their day-work program. For several years, he learned and developed gardening skills in their Garden Center, spending his days growing vegetables and going to places in the community such as Longview Gardens to help out in their gardens. Troy thrived in the day program- the structure and activities helped give more purpose and joy to his life, and provided him the opportunity to learn a new skills and socialize with peers. My parents were in their late 70s at the time, and were becoming increasingly worried about what would happen to Troy when they became too old or sick to care for him. Already, they struggled to keep up with his long list of specialist doctor appointments related to his several medical conditions. In 2015, a space opened up allowing Troy to move into Magnolia's community-based residential program. He moved into a home with 7 other men with developmental disabilities, and there is a full-time staff person there at the house with them. Since moving in, Troy has learned to do so many things for himself, and so much more than we had thought he was capable of. He has gained in independence and maturity, and now lives a full life. Troy helps in doing his laundry, cleaning up his room, choosing his own clothes to wear, helps with cooking, and his social life is full. He goes to programs at Magnolia daily during the week. They had to discontinue parts of their day work program after hurricane Isaac unfortunately, but they are trying to build back many components that were there before the storm. He exercises at the nearby park with his roommates and people from the community, he attends dances and parties in the weekends that organized by Magnolia or other community groups, and there is always something fun going on at Magnolia each week that he gets to participate in. My parents and I get to see and visit with him regularly, but his daily care does not fall upon my parents ages 89 and 83, and they no longer worry about what will happen to him once they are gone. They know he is in a safe place, with staff who truly cares for him and supports him. This special program of community based services has been instrumental and vital in helping my brother Troy live his best life. He would not have the experiences, opportunities, level of care, and independence if he were still living at home or if he was in an institution. It is the perfect level of support for him. I urge you to continue to support these services. He deserves to live his best life. These community based services have given him the opportunity to live his fullest.

Casey Jones, Shreveport, Louisianna

Dear Members of the Special Committee on Aging,

July 16, 2025 - When dinner time turned serious at The Arc Caddo-Bossier's Hoyte Community Home, three dedicated Direct Support Professionals (DSPs) sprang into action to save a beloved resident's life. Their quick thinking and skilled response prevented what could have been a tragic outcome and exemplified the extraordinary care provided daily by staff of The Arc Caddo-Bossier's community homes, residential houses where groups of 6-8 men or women with developmental disabilities live and enjoy actives lives together.

A Routine Evening Becomes a Life-Saving Moment

At dinner time on Wednesday, July 9th, 55-year-old Trey B., a resident with disabilities, who has called The Arc Caddo-Bossier home for more than 32 years, began choking on his meal. What happened next showcased the professionalism, training, and dedication of three remarkable DSPs who have devoted decades of their lives to caring for people with intellectual and developmental disabilities.

Georgia Carter, who has served The Arc Caddo-Bossier for nearly 25 years, recalls, "I turned around and looked towards Trey sitting at the table, and I noticed he was in distress". Without hesitation, she ran to Trey's side and began administering back blows.

Malcolm Cannon, an 18-year veteran DSP, immediately took over. "I attempted to help him, and he was starting to go down. His body weight was like dead weight, and we were attempting to keep him upright," Cannon explained. Working alongside Assistant House Manager Rasheeda Means, who has been with The Arc since 2000, the trio moved Trey to the adjacent living room to continue the Heimlich maneuver and the other life-saving efforts, following their training.

The three direct support professionals remained calm and focused and demonstrated the value of their extensive training in CPR, first aid, and emergency response. Carter called 911 while Cannon and Means continued working with Trey, adding the emergency operator's instructions to encourage coughing. With the support of 911 operator on the line and instinct and training at play, the team’s persistence paid off and the large piece of food that had been blocking Trey’s airway dislodged, offering immediate relief as color returned to his face and his breathing normalized.

"At The Arc Caddo Bossier, the safety and well-being of our residents is our top priority. We take great pride in our staff for their unwavering commitment, ongoing dedication to training, and their ability to respond effectively in emergency situations." says Deborah Hill, The Arc Caddo-Bossier's Director of Community Homes

For these three DSPs, saving Trey's life was more than professional duty - it was family caring for family. "I've been here 18 years, and the guys have become like family. It doesn't seem like a client-staff relationship. I've become close to all of them," Cannon shared.

Carter echoed this sentiment: "My kids are grown, so while these are not my kids, I can't go more than two days without seeing them."

"At The Arc Caddo Bossier, the safety and well-being of our residents is our top priority. We take great pride in our staff for their unwavering commitment, ongoing dedication to training, and their ability to respond effectively in emergency situations." says Deborah Hill, The Arc Caddo-Bossier's Director of Community Homes

Trey has been a cherished member of The Arc Caddo-Bossier family since March 26, 1993. Known for his love of sports, particularly volleyball and kickball, Trey has a special fondness for all holidays, with Halloween and his birthday being particular favorites. He participates in the Conly Day Program and brings joy to those around him with his enthusiastic spirit.

"Trey is a very lovable person. He smiles a lot," Carter described.

The Arc Caddo-Bossier opened the first community home in Louisiana in October 1977. This innovative approach proved that there could be alternatives for people with intellectual and developmental disabilities that would allow those who lived there to thrive. Today, The Arc Caddo-Bossier currently owns and operates eight community homes throughout Northwest Louisiana, serving more than 50 people with around-the-clock care.

Kristen Powers, Executive Director of The Arc Caddo-Bossier, takes the responsibility of carrying the torch of this legacy very seriously and is proud of the continued work of the organization to serve people in this unique and innovative way. “Our Community Homes meet each individual's needs through person-centered plans customized to every person who lives in one of our homes,” says Powers. “This incident exemplifies how well-trained, dedicated staff make this personalized care possible. We are so grateful to have caring, talented, experienced professionals like Rasheeda, Malcolm and Georgia on our team!”

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Maine

Roger Lambert, Kennebunk, Maine

Dear Members of the Special Committee on Aging,

Community living matters to me

Cathy Smith, Oakfield, Maine

Dear Members of the Special Committee on Aging,

Community living matters to me because wiithout I'd be homeless.

Don LaRouche, Skowhegan, Maine

Dear Members of the Special Committee on Aging,

Community living matters to me because everyone needs a place to live without fear

---

Lynne Spencer, Gardiner, Maine

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a special needs grand-daughter that has exceeded all expectations she'd acquire because of the services she received growing up. She was born with part of her brain missing, a hole in her heart and missing valves, and only one kidney. She will never be able to live alone but she is a wonder to us all. Thank God for all the services she received. Every disabled child deserves this.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Maryland

Sue Italiano, Parkville, Maryland

Dear Members of the Special Committee on Aging,

Community living matters to me because I have worked with people for 30 years that have been disabled and I myself have been disabled the last seven years. I've seen people who have no family and are dependent on programs like Medicaid, social security.....

Please realize that this is survival for many who are challenged by life circumstances.

Jennifer Dapkins, Olney, Maryland

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps give individuals independence, build skills in the real world, while in real time. They have better access to care, nutrition, and individual support vs. institutional services, which btw are under staffed, and filled untrained staff. They are infamous with abuse, neglect, and financial theft. Please don't take funding from community based programs.

Judith Weightman, Frederick, Maryland

Dear Members of the Special Committee on Aging,

Community living matters to me because I am approaching 86 years old. I cannot keep up with the dr. appointments my daughter needs. Her home and supports brings some independence to her as well as some social life. This is crucial to her well-being both mentally and emotionally. She is not able to read, write, cook, drive, shop, or understand dr. directions for her meds. This gives me peace-of-mind that she will be cared for as she ages. This is crucial for both of us.

Patricia Hollinger, Westminster, Maryland

Dear Members of the Special Committee on Aging,

Community living matters to me because it cared for my son Stephen. He could not walk, could not talk, had to be diapered, had to be fed, could not see or hear. Thankfully, he died two years ago at the age of 54.

Veronica Hippensteel, Pasadena, Maryland

Dear Members of the Special Committee on Aging,

Community living matters to me because my son has severe autism. I believe we need a place that is a cross between assisted living and institution living in addition to group homes for those that are not as severe. A place with some professional on staff. A place with some cameras to make sure there is no abuse. Non verbal with intelligence disorder is harder to deal with. There needs to be a fence around it to keep them safe. A movie-rec room so they can socialize together. This model will allow the staff to help each other when one of the clients is in crisis. i am also for the group homes for those that can live in them that can't live alone. I am also for supported staff coming to the client home to help keep them in the family home and their home if it is left for their use. Medicaid is how these people are taken care of. My son will always need a person with him due to his intelligence disorder and severe autism. We should take care of the ones that cant work.

Kevin Carbaugh, Mt. Airy, Maryland

Dear Members of the Special Committee on Aging,

The services that my 28-year-old daughter with Down Syndrome has received have changed her life significantly. These services give her a sense of independence that all citizens should experience.

Amity McGinnis, Laurel, Maryland

Dear Members of the Special Committee on Aging,

Community living matters to me because it is very import jet for people with disabilities have freedom and feel like a regular person and feels so special to them for their future

---

Marcia Canfield, Jefferson, Maryland

Dear Members of the Special Committee on Aging,

Community living matters to me because my son with Down Syndrome has friendships out side of the home and will be cared for when I(his mother) is gone.

Thank you

Judith Furie, Jessup, Maryland

Dear Members of the Special Committee on Aging,

Community living matters to me because our adult son is autistic and needs these services. He has benefited so much from the educational support, community support, and work support from The ARC of Howard County. He needs to be able to live with independence, dignity, and a deep connection to his community.

A.J. Brown, Hyattsville, Maryland

Dear Members of the Special Committee on Aging,

Community living matters to me because it gives society what it supposed to give it: LIFE

Kim Fauth, Catonsville, Maryland

Dear Members of the Special Committee on Aging,

Two of my five adopted child are or will be benefiting from Committee Living supports in their adulthood.

My daughter (21) is already a part of Maryland's Transitioning Youth program under DDA, living in a shared supported living apartment with rotating caregivers; and her brother (20) is slated to access his services next year.

Both have lifelong developmental disabilities. Things like managing time, handling money, scheduling appointments, making healthy eating, hygiene and sleep decisions all require external help. My husband and I could in no way provide 24-hour supports for both of them, in addition to all our other responsibilities. However, WITH the appropriate supports and accommodations, both of them have jobs, attend a social group for adults just like them, can cook basic meals, volunteer to help others, and our daughter can even drive in a limited, well-practiced area, like to work and church. Take the supports away, and they'd both be on screens, unbathed, missing their medication, and eating junk food; but WITH supports, they can live and work and commune with everyone in the community, give back, pay taxes, and have meaningful, productive lives.

We are VERY grateful for their supports and to know they will be cared for after we are gone.

Thanks for taking the time to read our story.

Robert Taishoff, Annapolis, Maryland

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter Jackie is 24 years old and has Down Syndrome. She has participated in community based support program through the DDA waiver process in Maryland. She has 1 to 1 support person that takes her to all of her community based activities including work at the YMCA; horseback riding; bowling; movies and social events.

The largest drawback with the current system is the lack of portability if we were to move to a different state her services do not follow her. This needs to be fixed. Jackie benefits from these services and would have no independence if these. Support service went away.

Gayland Carlisle, Greensboro, Maryland

Dear Members of the Special Committee on Aging,

Community living matters to me because the quality of life for my adult disabled child allows him to not only be a blessing to his family, friends, and larger community, but his needs are managed so efficiently (by family who knows them intimately) that the impact cost of caring for his needs are lessened on a small rural community's already limited social service infrastructure

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Lorretta Sisco, Rock Hall, Maryland

Dear Members of the Special Committee on Aging,

Community living matters to me because My Son Autistic with Other Diagnoses & Needs help With Everything

---

Sharon Brecker, Baltimore, Maryland

Dear Members of the Special Committee on Aging,

Community living matters to me because for a long time I wasn't part of a community but a burden to it. I was addicted and homeless and lost. I have since with the help of Medicaid gotten clean and have gotten my outs dated pacemaker with leads that moved and endangered my life without medical I could not have gotten that life saving surgery. Without good program snap I wouldn't be able to nourish my body to heal and have resources to get what I need to be healthy safe and alive to get my life back. That is what the public assistance has done for me. Without them id die definitely. My life is worth so much and so am I. Thank you for your time and consideration during these terribly trying sad times.

Rita Bueche, Towson, Maryland

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a School Sister of Notre Dame. We sisters worked for years teaching and ministering among the people of our nation. Now as we age, if we do not have the benefit of Medicaid HCBS we will be on the street. These are trying economic times. Without Medicaid HCBS we will have neither health care nor a place to live.

Tonya Gilchrist, Silver Spring, Maryland

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm able to make my own best decisions and follow my specific daily routine, surrounded by my family and friends and neighbors who know me. And an older mom with a physical disability, parenting can be especially strenuous. My teenage son receives autism waiver HCBS services that keeps our family together, functioning as one progressive unit towards our goals. His caregivers have become part of our family and help to keep us moving forward. If our son's HCBS services goes away, our functioning family might be stalled and split into pieces.

Arlene Paterrov, Clarksburg, Maryland

Dear Members of the Special Committee on Aging,

Community living matters to me because people like living near their friends and family. They want to keep their same doctors.

Melissa Sachs, Rockville, Maryland

Dear Members of the Special Committee on Aging,

Community living matters to me because I do not want to lose my services

---

SERVICE COORDINATION

December 8, 2025

The Honorable Kristen Gillibrand
Ranking Member
Special Committee on Aging
United States Senate
G16 Dirksen Senate Office Building
Washington, DC 20510

RE: United States Senate Special Committee on Aging Hearing Regarding the Importance of Community Living for Older Adults and People with Disabilities. Delivered via email to hcbs@aging.senate.gov.

Dear Ranking Member Gillibrand:

On behalf of Service Coordination, Inc. (SCI), thank you for holding a hearing about the importance of community living for older adults and people with disabilities and the opportunity to provide the U.S. Special Committee on Aging a statement for the record, "Aging in Place: The Impact of Community during the Holidays". With this letter, we submit stories from three Maryland seniors about the importance of Home and Community Based Services (HCBS). HCBS are essential for people with disabilities, older adults, and people with complex medical needs. We especially appreciate the committee's dedicated focus on the value of HCBS services.

Service Coordination, Inc. (SCI) is a nonprofit, providing conflict-free case management services and advocacy for more than 16,000 people of all ages with disabilities and medically complex needs across Maryland. SCI is the largest nonprofit case management organization in Maryland, and we employ over 1,200 team members, many of whom are Coordinators of Community Services and Supports Planners, providing critical case management services for people enrolled in various Medicaid Waiver and State Plan programs. SCI helps people navigate complex systems by championing choice, fostering community, and nurturing connections.

HCBS Conflict-Free Case Management is Essential

Conflict-free case management is an essential aspect of delivering HCBS, designed to ensure that people receive unbiased support tailored specifically to their unique needs. This approach promotes individualized support. With an unbiased case management system, people are more likely to receive care that truly reflects their preferences and choices. Case managers explore a wider range of options, ensuring people have access to the most suitable services that meet their specific needs. Conflict-free case management stands as a cornerstone of an effective and trustworthy system for HCBS. By prioritizing independence and objectivity, this approach not only enhances the trust and accountability within the service delivery system but also significantly improves the quality of care for those it serves, ultimately empowering people to lead self-determined lives in their communities.

HCBS Waiver Services in Maryland and Criteria to Qualify

Maryland has made a significant commitment to its residents by choosing to participate in the Medicaid program, establishing a framework that emphasizes HCBS as a viable and cost-effective alternative to institutional care. This decision reflects a broader recognition of the importance of supporting people in their own communities rather than confining them to institutional settings.

Service Coordination, Inc.
5283 Corporate Drive, Suite 103, Frederick, Maryland 21703
301-663-8044, 888-240-6835 • info@sc-inc.org • www.ServiceCoord.org

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At the heart of Maryland's approach is the Medicaid state plan, which outlines various provisions and related authorities, such as demonstration projects and waivers, including the Community Options Waiver, Community First Choice Program, and the Community Pathways Waiver. These elements work together to create a system that prioritizes HCBS, enabling people to receive the support they need in the comfort of their homes. This not only alleviates the financial burden of institutional care but also promotes a higher quality of life for those receiving services. Eligibility for these vital services is carefully determined, with Maryland establishing clear criteria that consider factors such as income, functional ability, and the specific needs of individuals. This ensures that the support is directed toward those who require it most, including older adults, individuals with disabilities, and those managing complex medical needs.

HCBS aims to enhance the quality of life for people by offering services that significantly enhance their ability to live independently, participate in their communities and access vital services that promote their overall well-being. Furthermore, HCBS encourages family and community involvement, creating robust support networks that contribute to overall health and well-being. The flexibility and choice inherent in these services empower people to select the types of assistance they receive and how it is delivered, making their care experience more aligned with their personal values and needs.

Stories* Which Highlight the Value and Importance of HCBS Services
**Some names given are pseudonyms to protect privacy.*

Gary's Story

> *Gary is 54 years old and resides in Allegany County, Maryland. He is a successful construction business owner and traveled across the United States for work. After a severe work-related injury in 2024, he was unable to move anything below his neck. He described feeling "hopeless," facing a 99% chance of never walking again from numerous different medical providers and was institutionalized in a long-term care nursing facility.*
>
> *Within a few months, however, he began to regain limited mobility and was approved for HCBS services through the Community Options Waiver Program. With assistance from his supports planner, he explored non-Medicaid resources such as housing, financial assistance, legal support, transportation services, and other community-based services that would allow him to transition home safely. While his supports planner worked to build a foundation for independence, he pushed himself daily – walking more, training harder, preparing for a future and life he refused to give up.*
>
> *Since transitioning back into a community-based apartment, his recovery has been tremendous. He no longer uses any assistive devices and has regained most of his mobility. His social connections have strengthened, and he now spends time with friends and engages actively in his community. Most inspiring of all, his ambition has fully returned – he plans to re-enter the workforce, rebuild a business, and eventually resume traveling.*
>
> *When asked about how HCBS and supports planning services assisted him with reintegrating into the community and improving his health and ambitions, Gary stated: "without the support of HCBS and my supports planner, I would not have had access to the local resources that made safe housing, rental and energy assistance, and other community-based programs possible". Gary reports that these services allowed him to make a successful transition back into the community, something he would not have been*

able to afford or arrange independently. Gary also shared: "I believe without the support from HCBS personal assistance services, home delivered meals, nurse monitoring, and supports planning, I would still be in the nursing facility. If I did not receive assistance from the HCBS and my supports planner, I would not have the ambition, stability, and improvements in my overall quality of life that I am grateful to have today."

Gary says he "feels like a brand-new person," and credits his recovery to the opportunities, support, and independence made possible through HCBS.

Notably the cost of a semi-private room in a nursing home in Maryland is approximately $12,501 a month, about $150,012 a year[1]. The HCBS services that Gary accessed included personal assistance, meal delivery, nurse monitoring, and supports planning. These supportive services cost approximately $27,000 a year and were covered by Medicaid.

Mary's Story

Mary is 77 years old and resides in Harford County, Maryland. She was at risk of being forcibly removed from her home due to the absence of necessary supportive services. Her health had been declining, and she was no longer able to care for herself or maintain her living environment. She was unable to take out her trash, resulting in rotting food and soiled adult briefs remaining in the home for extended periods. She also had significant difficulty with mobility, including accessing the bathroom, which prevented her from showering and maintaining personal hygiene.

Since the initiation of HCBS services through the Community First Choice Program, her personal condition and living situation have improved dramatically. Through her personal assistance services, her trash is now regularly removed, she can move to and from the bathroom safely and is provided with hygiene assistance in her home. She also receives a Personal Emergency Response System which allows her to contact emergency services through the push of a button. Further, her nurse monitor and supports planner come into her home routinely and provide housing and safety checks to ensure her apartment remains in good condition and she is safe. As a result of this support, she has been able to remain safely in her home and has avoided placement in a nursing facility. These supportive services cost approximately $25,000 a year and were covered by Medicaid.

Freddy's Story

Freddy is 71 years old and has resided in both Frederick and Harford County, Maryland. In 2024, he lived with his two sisters alternating between their houses. Although he used a walker and could feed himself, his balance and upper-body strength were declining, making it difficult for his sisters to care for him. A priority assessment through HCBS programming in November 2024 found he was no longer safe in their homes due to his worsening mobility and the homes' limited accessibility.

He applied for HCBS services in December of 2024. During the review process, his health declined further; he became fully dependent on his wheelchair for mobility, needed help eating, and was hospitalized twice, with the second stay leading to spinal surgery and rehabilitation care. With consistent physical therapy, he

[1] U.S. News and World Report, "Nursing Home Costs and How to Pay" November 26, 2025: Nursing Home Costs and How to Pay | U.S. News

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gradually regained mobility and returned to using a walker. He was approved for the HCBS Community Pathways Waiver in February 2025 and began residential and day services in April of 2025.

He happily transitioned into his new residence, decorating his room with family photos, sports memorabilia, and his collection of antique diecast coin banks—plus a stash of cookies and his bowling ball. His day program quickly became the highlight of his week. He has made many friends, found a girlfriend, enjoys regular outings, and goes bowling every Friday.

Today, thanks to HCBS supports, he is thriving, living safely, staying social, exploring the community, and fully embracing life.

We are deeply grateful to the Senate Special Committee on Aging for inviting stories and lifting the experiences of Medicaid beneficiaries who receive HCBS waiver services. Please consider SCI a resource to you and your staff. For further information, please contact Sarah Christa Butts, Vice President of Government Relations at Sarah.Butts@sc-inc.org or 240-741-2273.

Sincerely,

Tenneille Aleshire, Executive Vice President and Chief Program Officer

cc: Hon. Angela Alsobrooks

Service Coordination, Inc.
5283 Corporate Drive, Suite 103, Frederick, Maryland 21703
301-663-8044, 888-240-6835 • info@sc-inc.org • www.ServiceCoord.org

Statement for the Congressional Record

Re: Importance of Community-Based, Dementia-Capable Housing for Adults with Intellectual Disability

Submitted to the U.S. Senate Special Committee on Aging

My name is Dr. Seth Keller, and I am submitting this statement to highlight an urgent national need: the development and expansion of community-based, dementia-capable housing and supports for adults with intellectual disability (ID) who develop Alzheimer's disease or other dementias.

I write not only as a practicing neurologist, but as a long-standing national leader in IDD health. I serve as Co-President of the National Task Group on Intellectual Disabilities and Dementia Practices (NTG), I am the Past President of the American Academy of Developmental Medicine and Dentistry (AADMD), and I am the founder and past chair of the American Academy of Neurology's Adult Intellectual and Developmental Disabilities Section. Through these roles, I work closely with families, policymakers, clinicians, disability service systems, and HCBS providers across the country and internationally. My perspective comes from decades of neurology practice and national leadership dedicated to improving health equity for people with lifelong disabilities.

The Urgency of the Issue

Adults with intellectual disability—particularly those with Down syndrome—are living longer, a tremendous public health achievement. Yet with longer life expectancy comes a dramatically higher risk of dementia. By ages 55–60, the majority of adults with Down syndrome will develop Alzheimer's disease. Families, siblings, providers, and state systems increasingly struggle to respond to these needs because our long-term care infrastructure was never built with this population in mind.

Daniel's Story

Daniel lived for decades in a small, state-licensed group home. He enjoyed music, bowling, and community activities. His caregivers knew him deeply—his routines, joys, humor, and communication style. HCBS supports allowed him to lead a meaningful community life.

At age 52, subtle cognitive and behavioral changes emerged. He was eventually diagnosed with Alzheimer's disease—a diagnosis tragically common in adults with Down syndrome.

As his dementia progressed, his home lacked the physical environment, safety features, and dementia-trained staff needed to support him. When nighttime confusion and seizures began, the provider agency felt unable to safely support him and transferred him to a nursing home.

Daniel was uprooted from his familiar life and placed in a large institutional setting where few understood his lifelong disability or the dementia trajectory unique to individuals with Down syndrome. His sister later said, "He didn't recognize anyone. He stopped smiling. He just disappeared."

Daniel died within a year.

What failed Daniel was not his dementia. It was the absence of community-based, dementia-capable housing and HCBS supports designed for adults with lifelong disabilities.

Why Dementia-Capable HCBS Is Essential

Adults with intellectual disability have the same right as any American to age in the community. Without appropriate HCBS supports:

1. People are forced into nursing homes when their needs could be met in the community.

2. Families—often aging caregivers in their 70s and 80s—face crises they cannot navigate alone.

3. Provider agencies lack training and infrastructure, leading to preventable hospitalizations, trauma, and early mortality.

Policy Recommendations

To protect Americans like Daniel, I respectfully urge Congress to:

- Strengthen Medicaid HCBS funding to support dementia-capable housing, day services, and care models.

- Invest in dementia-specific training for direct support professionals (DSPs).

- Encourage states to create IDD-inclusive dementia plans aligned across aging and disability networks.

- Support cross-system collaboration between disability services, aging services, and health systems.

- Improve caregiver supports, including education, respite, and navigation services.

Closing

Through my leadership roles with the NTG, AADMD, and the American Academy of Neurology, I have witnessed the transformative impact of dementia-capable HCBS—and the consequences when it is absent. Daniel's story is not an outlier; it reflects a national pattern that must be addressed.

Community-based dementia-capable housing is clinically effective, cost-efficient, and essential to preserving dignity, autonomy, and quality of life for individuals who have been valued members of their communities throughout their lives.

Respectfully submitted,

Seth Keller, MD

Co-President, National Task Group on Intellectual Disabilities and Dementia Practices

Past President, American Academy of Developmental Medicine and Dentistry

Founder & Past Chair, AAN Section on Adults with Intellectual and Developmental Disabilities

Cherry Hill, New Jersey

sethkeller@aol.com

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Massachusetts

Nancy Garrett, Amherst, Massachusetts

Dear Members of the Special Committee on Aging,

Community living matters to me because both my stepson and stepdaughter live in residential housing. My stepdaughter, who is higher functioning than her brother, is able to work at McDonald's and study for her GED. Also, her house manager has taken her under her wing. They've traveled to Salem, MA, and New York, where they did many fun activities together. If it weren't for her program, she wouldn't have this enrichment in her life.

My stepson, who needs more help, attends a school for adults with special needs. He gets wonderful individualized care. He is well liked there. At his residence, staff faithfully bring him the 30 miles every Saturday, there and back, to visit his Dad and me.

My stepson is 37. My stepdaughter is 32. They both have an excellent quality of life at their HCBS, and I don't know what they'd do without them.

Joe Parzych, Greenfield, Massachusetts

Dear Members of the Special Committee on Aging,

Community living matters to me because. I want keep being independent and ect.

Eileen Velez, Boston, Massachusetts

Dear Members of the Special Committee on Aging,

Community living matters to me because it is so much healthier and rewarding then being in a group home.

Maureen Cumming, Lynnfield, Massachusetts

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a child with disabilities and I care about families with all types of disabilities. We should be adding to the programs, not decreasing the programs.

Mary Richinick, Westminster, Massachusetts

Dear Members of the Special Committee on Aging,

Community living matters to me because my brother, who has developmental disabilities as well as physical health issues, lives in a group home along with 3 roommates who also are disabled. The staff works hard to make a nice, pleasant and safe home for these individuals. They attend to the many needs of the residents to keep them comfortable and happy. My brother is doing well under their care and is living a happy life. He loves his roommates and his home. He is unable to care for himself and he needs the care and support of the staff at the home to keep him healthy.

Robin Marques, Lakeville, Massachusetts

Dear Members of the Special Committee on Aging,

Community living matters to me because I began my career working in an institution which housed people with ID/DD. Housed is a term I use loosely. Warehoused better represents the experience of the people kept there. I transitioned into the community with individuals who had no basic home living experience. No refrigerator, no separate rooms to sleep and live in. It was a shock for many folks who spent their lives living and sleeping in a room with 15 or more other people to have a room to themselves. It took a bit of getting used to. Once people realized that they had their OWN personal space, the reaction was beautiful. Imagine never being able to call something your own...and then you can.
The community also offers the opportunity to get to know people and make friends. Friends are people who care about you and are concerned for your wellbeing. Sadly, I have experience too many funerals where of the 10 people in attendance only 1 or 2 were not paid to be there. Living in the community and joining groups, attending church, being seen around town has led to relationships which ease the loneliness felt by many marginalized members of the ID/DD population. I cannot imagine going back.
Please support opportunities and funding to keep the progress going in a forward direction. None of the people I know want to go back to the warehouse that is an institution.
I have been supporting people for 45 years. There is still more work to do.

Jennifer Mock, Oxford, Massachusetts

Dear Members of the Special Committee on Aging,

Community living matters to me because my husband and I have two additional needs children. We are in constant fear for the future. We both try to keep ourselves as mentally and physically health as possible so we can live as long as possible to protect and care for our children. Sleepless nights worried about what will happen to them when we die.

Luxanyaris Zayas, Hudson, Massachusetts

Dear Members of the Special Committee on Aging,

Community living matters to me because my son who is autistic and non verbal benefits across multiple communities. He needs this in order to live a life of fulfillment within his communities. He currently lives with us his immediate family and he attends a day program as well where he does community service as well as participate in many community programs for elderly and/or disabled individuals both adults and children. He has been so happy at participating and enjoying spending time with his peers and staff as well as therapists and providers. Please help us maintain these benefits so our children can continue their path to independence and a live filled of fulfillment and happiness. Thank you!

Nick Figueredo, Springfield, Massachusetts

Dear Members of the Special Committee on Aging,

Community living matters to me because people should feel included in society just like anyone else.

Aleksandra Goldberg, Foxborough, Massachusetts

Dear Members of the Special Committee on Aging,

Community living matters to me because my son is about to graduate high school. He has autism and epilepsy. Without support he would have to live at home and this would be very detrimental to his mental health and his self efficacy. I work with older adults in my professional life as a Physical Therapist. They want to be in their own home most of all. Without support they would need to be institutionalized sooner at a greater expense to them or to the taxpayer. Please help my son and my patients live independently with support in their homes as they need. It means the world to us!

Sally Ruscito, Dedham, Massachusetts

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a relative who has achieved so much in that setting.

Heidi Roberts, Plymouth, Massachusetts

Dear Members of the Special Committee on Aging,

As a 24 year old woman who hears using cochlear implants and has intellectual challenges, my daughter Hannah would have a very limited ability to actively engage in her community and have meaningful, enriching experiences with social peers without access to Medicaid funded home and community based services.

Hannah is wonderfully outgoing and is up for any and all experiences. Today Hannah was able to participate in her day program where she came together with several friends to volunteer for Meals on Wheels to deliver lunches for seniors in Plymouth, MA. Her senior friends look forward to her visits as much as she eagerly anticipates seeing them and their pets. She knows every senior by name and remembers their birthdays flawlessly. Later, she went to a local horse rescue and assisted in caring for her favorite injured or elderly equines. Following that, she returned home to her 2 room mates and a personal care assistant who helped the girls make dinner, take showers and relax with holiday craft projects. Each night she calls and gives me an update on how her day went. She is always happy to share her activities and plans and to report on new horses at the barn or a mother cat who just delivered kittens at the animal shelter where she also volunteers. It's with great pride that she notes she lives "in an apartment like my big brother" and has an independent, though highly supported life. She sees meaning and value for the volunteer work she engages in and gets excited to plan her schedule each week.

If these residential and community services were taken from Hannah, she would need to return to living with me. This would drastically limit her social options and daily activities. She would be heartbroken without her varied and active program. It would also require that I no longer work as a geriatric speech pathologist providing hands on care for stroke, accident, cancer and rehabilitation patients. My job cannot be performed remotely and the financial loss would be devastating to us. Without community and home based services I would have to replace my roles as a her mother, friend, shopping buddy, gardening pal or coffee date and become her full time caregiver instead. Whereas I know I can provide for her physical care, I could never give her the enrichment that her Medicaid home and community based services allow. Loss of services would be heartbreaking to us, as well as Hannah’s senior friends, her animal friends and her large social peer group. It would also remove much needed speech therapy services from our local nursing home. Removing Medicaid HBCS would remove so much of value from more than just the direct recipients, it would diminish our whole community. Please continue to support the programs that bring health, happiness and community engagement for adults with disabilities.

Heidi Harrington Roberts

James Ivy, Hinsdale, Massachusetts

Dear Members of the Special Committee on Aging,

Community living matters to me because of the people that I serve as an employee at Berkshire County Arc. Without the services that we provide, over 800 people would not have the opportunity to pursue their dreams of living an independent life and being a part of the community.

James Scott, Whitman, Massachusetts

Dear Members of the Special Committee on Aging,

Community living matters to me because
I've had the extreme privilege to work with and for the men and women of New England Village inc for 35 years
I've seen the the potential and opportunities to learn, grow and get competitive employment because of the services they received and the direct care support they received in their community setting
They live longer happier lives in community base settings
I have celebrated 70, 80 and even 92 year-old birthdays with my residents
Because of the care they've received

Alice Taylor, Waltham, Massachusetts

Dear Members of the Special Committee on Aging,

Community living matters to me because without it, my autistic son would not have the supports he needs. He is in a 24/7/365 behavioral group home, for which he waited 7 years. I had to get old and sick in order for him to move up the priority ladder and move out of my home. He outweighs me by 100 pounds and is 8 inches taller. Adults with severe autism/ID/DD are not going away and need a variety of housing models. He is in a 5-person group home because that is the only current model available to support him. "Shared living" would mean the provider can evict him when his care is "too much to handle." Believe me, that would not work for him.

We signed the Medicaid/HCBS waiver because at least that way, our state can get some federal funds, financial help, for providing housing and supports for people with disabilities. Social Security alone would not be enough to pay for rent and supervision for him.

We need other options for severe autism such as farmsteads, intentional communities, and intermediate care facilities. Community can be defined different ways and safety should be a priority.

Sofia Montemayor-Thomas, Acton, Massachusetts

Dear Members of the Special Committee on Aging,

Community living matters to me because I care about the elderly.

Michael Driscoll. Duxbury, Massachusetts

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows the disabled to support one another and have active lives.

Heather Watkins, Roslindale, Massachusetts

Dear Members of the Special Committee on Aging,

I have Medicare primary and MassHealth (MA version of Medicaid) secondary for insurance coverage. They pay for vital personal care attendant (PCA) services and durable medical equipment (DME) like customized manual wheelchair I received after 6 level completion process and nearly 4 months. I also use a non-invasive vent to assist breathing when sleeping/laying down due to compromised respiratory muscles from a congenital form of muscular dystrophy. The vent runs about $3500 per month and without insurance coverage would not be affordable and I'd risk respiratory failure without it's use. This loss of DME coverage and PCA services would not only impact me but also my family and my advocacy work. The impact would not be static but spiral out and have broader implications to community overall beyond myself and many disabled persons (apparent, non-apparent, chronic illness) I know live in similar continuum.

My mother is 74 and has same coverage, uses PCA services that help with meal prep, hygiene, light housekeeping, shopping, clinic escort, home management. She also has visiting nurses who help with psychiatric and diabetic care and continuity of med intake. These in-home services allow her to remain community-based and independent. She is able to age with grace, dignity, and autonomy and participate in community as much as she is able to do so.

Having beneficial policies with budget allocations aid individuals, families, and whole communities to thrive.

Muriel Slack, Abington, Massachusetts

Dear Members of the Special Committee on Aging,

Community living matters to me because I am on disability. Harbor one Bank told me I have to remove $50,000. Because on disability I can only have $2000. In the bank. Is this true?

Jessica Roy, Wareham, Massachusetts

Dear Members of the Special Committee on Aging,

Community living matters to me because I have 2 disabled teenagers level 3 autism? epilepsy, pica. They need the state to stand up for them and stop cutting their funding. Vets and special needs people need more

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bbbbbWritten Testimony to Congress: Rebalancing Medicare and Medicaid Spending

Chair Members of the Committee,

Thank you for the opportunity to submit this testimony on an issue that goes to the heart of fiscal responsibility, federal–state partnership, and the rights of elders and people with disabilities. My testimony is based on more than 40 years of lived experience as a C4 quadriplegic paralyzed below the shoulders living in the community thanks to Medicaid-funded Home and Community-Based Services (HCBS), over 20 years of professional work on Long-Term Services and Supports (LTSS) policy, and 15 years of work focused on Medicare–Medicaid integration.

The most cost-effective strategy for reducing federal Medicare spending and state Medicaid spending is sustained federal investment in HCBS. Yet the proposed federal disinvestment outlined in HR 1 directly contradicts this truth. As someone who believes Medicaid should be effective, efficient, and economical, I cannot find a compelling argument for cutting the Medicaid program or for the federal withdrawal from its commitment to supporting states that invest in HCBS.

- Cost-effective: According to the Kaiser Family Foundation (KFF) and other sources, HCBS costs substantially less than institutional care, often less than one-third of the per-person cost of nursing facility placement.

- Favorable outcomes and preferred option: HCBS conforms with the preferences of over 90 percent of older adults who want to remain at home in their communities. States that have invested in HCBS see reductions in avoidable hospitalizations, emergency department (ED) visits, and institutional expenditures, leading to real Medicare savings.

- Regressive and counterproductive: At a time when states are making measurable progress toward rebalancing LTSS away from institutions and toward community settings, planned federal cuts threaten to reverse those gains. States that have worked hardest to rebalance LTSS spending are now being punished for doing the right thing.

- Compound existing HCBS gaps: The HCBS system is already experiencing access problems resulting from workforce shortages, which research has shown are tied to low wages. Continued wage reductions will exacerbate existing challenges.

My own life makes the stakes clear. Because of HCBS, I have been able to attend graduate school, build a career in public health, and live independently in the community. I am grateful for the life I have, but now worry as I approach age 65 that cuts to the service I rely on may force me, against my will, into a nursing facility. Institutionalization would mean increased Medicare costs and a shortened life spent in a cycle of ED and hospitalizations caused by

neglect, abuse, and preventable complications like decubitus ulcers and infections, as documented by organizations like Justice in Aging and the Commonwealth Fund.

Not only do I worry about myself, but I worry about people with intellectual and developmental disabilities, people with mental health diagnoses, and those with substance use disorder. What kind of statement will Congress be making if it denies these populations the opportunity to live in the community at increased cost to taxpayers?

The current system is misaligned and leads to wasteful spending on preventable ED visits, hospitalizations, and institutionalization. This wasteful spending will be exacerbated by further Medicaid cuts and the federal government's retreat from HCBS investment. A structurally unsound system is created when federal Medicaid cuts are combined with misaligned Medicare payment incentives, penalizing states for investing in cost-effective community care.

- Medicare Savings Mismatch: Under current law, states do not share in the Medicare savings they generate, even when those savings are directly attributable to their Medicaid-funded HCBS investments.

- Medicare Advantage (MA) Discrepancies: MedPAC estimates that MA plans are paid, on average, 20 percent more per enrollee than traditional Medicare would have spent, totaling tens of billions of dollars in excess federal spending annually. Furthermore, a recent Senate investigation found that MA plans spend roughly 10 percent on administrative costs, compared with under 2 percent in traditional Medicare, including billions in annual broker commissions. These expenditures do not improve Medicaid outcomes or reduce state LTSS spending.

States face a fundamental question: Why should scarce Medicaid administrative dollars be used to support MA plan administrative costs when the plans have not demonstrated reliable reductions in preventable ED visits, hospitalizations, or nursing facility expenditures? Every dollar a state invests in MA alignment without demonstrated savings is a dollar diverted from HCBS that keeps people in the community.

Congress should act decisively to realign federal policy with fiscal evidence that advances the rights of elders and people with disabilities under the Americans with Disabilities Act and Olmstead. Action requires a shift in federal–state financial signals to support the system that demonstrably works:

- Protect and strengthen federal Medicaid funding for HCBS.

- Rebalance federal–state financial incentives by sharing Medicare savings with states that reduce institutional use and hospitalizations through HCBS investments.

- Require MA and Dual-Eligible Special Needs Plans (D-SNPs) to demonstrate measurable value resulting from increased investment in Medicaid LTSS and behavioral health diversionary services, not merely reductions in Medicare spending.
- Ensure that no federal policy creates perverse incentives that push older adults and people with disabilities into institutions simply because short-term savings and costs fall on different sides of the federal–state ledger.

Rebalancing Medicaid spending toward HCBS, and rebalancing Medicare savings so states share in the benefits, is the most fiscally responsible, evidence-based, and morally sound strategy available to Congress. It protects individual human and civil rights, reduces federal and state expenditures, and strengthens the long-standing commitment to keep people in their homes and communities.

Thank you for your attention and for your commitment to policy that reflects both sound economics and fundamental human dignity.

Sincerely,



Dennis G Heaphy, DMin, M.Div., MPH, M.Ed.

U.S. SENATE SPECIAL COMMITTEE ON AGING

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DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Michigan

Sarah Carmany, Kalamazoo, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me as a person with Autism Spectrum disorder which is my primary diagnosis and Bipolar 2 disorder as my secondary diagnosis because I like so many of us with disabilities want to live and be apart of the community in which we live. By having the Home and community based services we get to live Independently with the right accommodations and be just as productive as other non disabled individuals and live a life full of promise and prosperity just like everyone else does. In an institution people get locked away and never interact with non disabled people. In an institution people would sit around all day with nothing to do and not live life full of promise and prosperity and suffer with broken dreams. What kind of a life is that? Take my life for example I have never been in an institution myself but I have watched videos of people in institutions and I know just by watching the videos of people in institutions and I know that's not the kind of life I envisioned for myself or anyone to be in ever if they don't have to. So as I previously stated that my life wasn't in an institution. I went to school and went through young 5s and Kindergarten then grades 1-12 just like everyone else without a disabilities did and was put into special education with Individual Education Plan(IEP). Going back to the school I did at times struggle but I still learned how to read and write at a young age and some of my classes were general education while others were done in special education or the resource room. When growing up my mom taught me and my brother both to be independent she taught me basic skills to keep up a house so that when we got old enough we could live independently in our own places. The skills that she taught both of us is how to dusty and clean, and when we got old enough she taught us how to wash dishes and go to the laundromat and how to organize and throw things away ect. Now thanks to my mother I'm now an independent individual living on my own in a two bedroom apartment without help from staff and living life to the best of my ability. I do have some support like I do have a representative payee that helps me to budget out my money, a caseworker through my local mental health that is Medicaid paid for helps with my paperwork for recertification for my apartment and Department of Health and Human Services, and my Medicaid and Medicare, Plus I practice Supported decision making and I do have a circle of support meeting that meets monthly to help discuss big goals like going to school, getting a driver's license, keeping up my health goals ect. In the past I have had job coaches to help me to get jobs and I used to be self employed from 2009 til 2022. I had a housekeeping g business where I went and cleaned houses and at the end a commercial building. In July of 2022 I left the self employment business and worked for the local chapter of the Arc Community Advocates who advocates for people with disabilities at the Federal level, the state level, and the local or regional level. So all my life I have been taught to be independent and without the home and community based services I wouldn't be able to continued to be living independently. I would probably not be employed, or have a representative payee to help me with paying my bills ect. These home community based

services are the lifeline of keeping people with disabilities living Indendently. I also do volunteer advocacy work for the state and I have sit on many different boards as well. I currently sit on Self-advocates of Michigan(SAM) board of directors, I also serve on the National self-advocacy board called Self Advocates Becoming Empowered(SABE). None of this would be possible without the Home and Community Based Services or the Michigan Developmental Disabilities Council with the volunteer self advocacy.

Michael DuRussel, Midland, Michigan

Dear Members of the Special Committee on Aging,

Continued availability of Medicaid home and community-based services programs is important to me because they are essential to my daughter and son-in-law continuing to live independently in their own home. Both have worked in the past and receive Social Security Disability, Medicare, and Medicaid. My daughter, who is 58, was born with cerebral palsy and learning disabilities and in recent years has suffered from severe recurring depression. My son-in-law, age 57, also has learning disabilities, type 1 diabetes, and severe scoliosis. Despite this, he was able to drive and work in the food service industry until five years ago when the scoliosis resulted in spinal cord damage, causing considerable loss of feeling and coordination in his hands and legs. As a result, he and my daughter are now totally dependent on us and on in-home care through Medicaid HCBS for almost all of their everyday needs. My wife and I are 79 and 80 years old respectively and, although we are still involved in their lives on a daily basis, we could not begin to provide all of the support they need to live independently and could not provide for their future care as we become less able to assist them. Medicaid HCBS are truly a lifeline for them and for us.

Traci Phillips, Coldwater, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because disabled and elderly individuals rely on these services for their health and wellbeing.

Tina Miller, Free Soil, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because I am 66 yrs old. I have went through the worst 2 years of my life starting in 2023. I had cataract surgery in August and September 2023 that left me more blind then before the surgery.

March of 2024 I had a house fire. Was able to stay in my home with the support of a generator, but fuel for 32 days was $800 to run the generator. That left my savings at $0.
My truck was vandalized and repairs have cost me over $1,200. Still paying this off. Then I was foreclosed on my home of 30yrs for back taxes totaling $3,000. The treasures department would not work with me. I had $1,500 in my savings to give to them and the remainder to be paid the next month. Instead of excepting payments the sold my house to a housing development located in Texas. I am being evicted as of Friday the 21st of November. I was scheduled for court on that day, but was unable to attend. I live 25 miles away for town and do not drive. I as have recently been diagnosed with aggressive breast cancer. I am experiencing bad health at the moment. So I was unable to attend
The eviction process in court. My main concern is there are insufficient amount of housing in this area. Actually there is none at the moment. Most have waiting lists of over six months. I do not know what to do. I do not know where to go. I do not have anybody to help me. I have no family or friends. I have tried every organization that has been suggested for me with no luck. If there's anything that this area needs, it's senior housing and transportation for people living out of town.
If you have any solutions to these problems, please return my call. I need it badly.
Sincerely
Tina M Miller

Ashley Hafeli, Lake Orion, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because I have personal experience volunteering for individuals who have disabilities; I also worked with these individuals during my internship training for my Music Therapy major, and I myself am diagnosed with Autism Spectrum Disorder. Therefore, it would mean a lot to me if you kept the Medicaid HCBS and continue making it more accessible and known to individuals who are not familiar with it.

Pauline Bynum, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because it takes a village not only to raise a child but to raise up one another. Being born different shouldn't mean having less value or experiencing less in life, community living allows us all to live life to one's full potential. Why would anyone want to take that away from another person?

Frank Vaca, Potterville, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because living authentically besides being hooked up to a tv or Nintendo switch 2. Going to pride events and book clubs.

Donna Carr, Center Line, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm a 61 year old mother and grandmother my parents are both deceased my mother passed away in 1987 of brain cancer I was only 23 I my father was a Korean war veteran he died in 2019 of a stroke I receive food stamps and insurance through the state of Michigan I have not been able to find a job since 2006 I have health issues and I make it known on my applications because I do not lie I have an avm on the front left side of my brain, fibromyalgia, arthritis and frequent headaches but I do not qualify for disability I only receive $298 a month in food stamps and my health insurance and if I lose that I will not be able to eat or take care of my health needs it's not that I don't want to work it's because no one is hiring people like myself

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Michael Larsen, Jackson, Michigan

Dear Members of the Special Committee on Aging,

See deafmed, my name, not my disability or what I did for a job. I'm listed on deafmed, find me and see many others too like me. Vocational training and rehabilitation helped immensely, thank you. Now, I'm navigating being old. I don't get paid weekly as a traveler anymore, not even biweekly anymore, it's monthly. I'd appreciate resources.

Milaine Grossbard, Southfield, Michigan

Dear Members of the Special Committee on Aging,

My daughter just entered her forever home last May. We thought she was a bit young at 26 but a spot open in her perfect location and we took it.
Many months later I asked another parents how his daughter was doing g and he used a word that never came to mind. He said she is becoming very “independent” this is a world in my wildest dreams I could never imagined describing my own daughter yet he said it all. My daughter,

leaving our home and my micro managing, with the excellent direct care workers had become independent!! It is something I never imagined as an option and because of these homes she achieved greater then ever thought, while surrounded by a family of ladies, a caring staff and a company, Jarc, that puts there residents first!!

Milaine

Beverly Spires, White Pigeon, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because I am retired living in social security with Diabetes. If I can't get assistance I won't be able to afford my insulin. I also gave a great granddaughter with severe cerebral palsy is her mother cannot receive HCBS they will become homeless and unable to get her the therapy's she needs

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Amber Beery, Saginaw, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because five years ago a woman walked up to me at church. "Do you want to be my penpal," she asked, by which she meant did I want to be friends who had coffee dates and baked cookies and played card games and sat together in church and called each other and celebrated birthdays and gave gifts and bemoaned snow and celebrated summer. We've been "penpals" ever since. My friend is in her 50s, has an intellectual disability, and has no family that cares for her. Her home is in community living. Without community living, she would not have safety, dignity, or the simple daily companionship that contributes to her flourishing. Community living has changed her life, and she in turn has changed mine.

Richard Smith, Melvindale, Michigan

Dear Members of the Special Committee on Aging,

TRUMP HAS TO BE STOPPED, HE OBVIOUSLY HATE THE DISABLED, WOMEN, CHILDREN AND VETERANS AND THE AGED.

Maxxcell Higdon, Lake Orion, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because I believe they should be safe, fun and free for people of all diversity to thrive in

---

Beth Kohler, Monroe, Michigan

Dear Members of the Special Committee on Aging,

He was just a baby, born with Williams Syndrome, when I realized how hard he would have to fight for the life we had dreamed for him when I was pregnant.

As an adult, he wanted to work. He wanted his own money and the pride that comes with earning it. He needed more than the 90 days that rehabilitative services allow for job coaching. Because of HCBS, he was able to hire a job coach to work with him until the employer said "we've got this." Now 27 years old, has held a job for over four years with natural supports.

As he has watched his high school classmates go to college, get jobs, have their own homes, get married, he has wanted that too. Nobody wants to live with their parents forever. Because of HCBS, he now lives in his own home, with a roommate, and the 24 hour staff required to support them safely in that home. The staff, who also needed jobs, are now working in a meaningful field and contributing to the economy and supporting their families. One who actually wants to go back to school to become a social worker so she can help more people like my son live their lives to the fullest.

This is all thanks to HCBS.

Stephanie Meacham, Marysville, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. HCBS help make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.

Skip Bleecker, Mount Pleasant, Michigan

Dear Members of the Special Committee on Aging,

People with disabilities and older adults deserve to live with independence, dignity, and

connection to their communities. HCBS help make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.

Bethann Robins, Kalamazoo, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because I have worked in institutions, and raised my son with severe impairments at home. The difference in quality of life between these settings is staggering. If one has ever been admitted to a hospital for a week or more, one can imagine what their life would be like if that was where they were permanently "placed." Institutional settings are not healthy for anyone. Close proximity creates rises in communicable disease, and increased hospital admissions as a result. The individual is more often than not enslaved to institutional routines- like staff mopping floors in the middle of the night, or being taken out of bed at 3am to be showered because that's what's convenient for staff. Meals are often cheap and lacking nutrition. Houses, like group homes, are often lacking cleanliness. Build up of dust and other allergens goes ignored. A look in the cupboards at dishes people are fed from will reveal, too often, food that has been baked on by a dishwashing machine. Staff are too frequently underpaid, overworked, and mistreated/abused if they develop any sort of connection with residents, and try to advocate. This translates to the quality of care they give the human beings they were hired to care for. Guardians and family members are retaliated against if they try to advocate. Executives earn lucrative salaries while rarely visiting the institutions they oversee. Families like mine, a single mother and a disabled adult child, are forced to give their child up to a system that uses that person as a funding magnet, receiving funds that are mismanaged to the detriment of that individual. I became disabled myself trying to care for my son at home. I was then told there were no more funds available to keep my child home, safe, and thriving. When the system took him, it was paid 5x the amount it paid my son and I put together through SSDI and Adult Home Help. I watched his quality of life deteriorate, watched him fail to thrive, after 2 decades of fighting for him, fighting for his life to be one in which he could smile, and laugh. I watched the light go out of his eyes, then I watched him die of aspirate pneumonia, after years of advocating for better staff training- as in not feeding him too fast for him to swallow, and making him literally inhale his food. By the time they realized something was wrong, the hospitalists said it was too late. If my son and I had been granted half of the funds it took to take him away from me and put him in a place that would eventually kill him, I could have kept him at home until his natural end. I could have hired help so I did not work myself into exhaustion leading to neurological disability. I could have continued educating people about people like my son, and what they give to the world by their existence alone- joy, knowledge of the spiritual and divine, how to be good humans. But that was all taken when he was. When the system decided to spend 5x the money to put him in an institution, and the subsequent hospital admissions that cost even more, and cost him his life. I still dream of what life could have been like if "The Village"

actually existed, and it had helped me keep him home and safe and happy. This is what Medicaid, when spent appropriately, can help people do-stay in their community, with their families, and friends, contributing their particular gifts and teaching what we can not otherwise learn. Please be The Village. Be one of the reasons people like my boy get to stay where they are loved, and safe

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John Gedda, Rochester Hills, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because my very disabled son has lived in an apartment for 20 years with parent help. Who will do the paperwork when we are gone? Who will hire needed support services like cleaning (which he can pay for) after we are gone? I'm a boomer. Our adult disabled children will be a big issues after we start to die.

Lisa Chadwick, Detroit, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because if I did not have this access I would be unable to live independently

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Jonathan Howlett, Eastpointe, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because it has without exaggeration, saved my family's lives. My brother has autism and is on the severe side of the spectrum. He has just spent his first year in a Medicaid HCBS group home and he is positively thriving. My parents took care of him for thirty years prior on their own and despite their best efforts, it was killing them taking care of my brother. Instead of spending their retirement years living well earned rest, they were still taking care of a strong, high needs adult. As they have aged they were not able to keep up with his needs alone. My brother could not go outside the house ever because my parents could not control him. As a result, they were all prisoners in their home. My brother exhibited violent behaviors due to his imprisonment and would lash out at my elderly parents. I spent many nights living in fear that I would get a phone call that my brother murdered one or both of my parents. But then my parents finally asked for help by the state. My brother initially spent some time at the Caro State Hospital where he learned management skills for his behaviors and his medication was adjusted to a proper dose. When he was stabilized, he then joined a HCBS group home and not only has his life improved but so too did my parents'. My brother is smiling, looking

healthier, and doing things in the community for the first time in decades. My parents are also improving. They are less sullen and haggard in their expression, they are able to spend quality time with other family members, and can go out to a restaurant together for the first time in twenty years. It is no coincidence that their increased happiness and health started when my brother moved to a group home. Medicaid HCBS programs save lives. Without them my parents would undoubtedly live shorter lives, my brother would be still the angry, restless person he once was, and I would still be living in fear of what happens to my family when a crisis inevitably occurs. Medicaid has been attacked quite a bit in the last few years. I believe the people responsible for these reductions want to reduce costs but at the end of the day, these reductions just cost Americans more in so many ways beyond just money. Do not reduce Medicaid HCBS programs, people's lives depend on it.

Christina Skeltis, Macomb, Michigan

Dear Members of the Special Committee on Aging,

I am writing on behalf of my 37 year old nonverbal, severely cognitively impaired and autistic brother. After the unexpected death of his mother and sole caretaker 6 years ago, he was left with no where to go and began residing in a community supported group home. We were so grateful to find a great place for him and he has since thrived. If not for his services, he would not be able to survive. He requires 24/7 care and supervision. He needs help with all personal care needs, safety, and health issues. Because of his supports, he is able to live in the community, attend skill building, and lead a decent life. Without these services he would have no where to live and wouldn’t be able to have his basic human needs met. His needs are too great and the loss of these services could cause him serious harm. These services are vital for the survival of this community. They deserve care and dignity and cannot help themselves. There are no other options for these people and their dependence on these services must be recognized and valued. These services are life changing for all involved and must be protected at all costs.

Diana Bush, Dansville, Michigan

Dear Members of the Special Committee on Aging,
Community living matters to me because it had made taking care of my adult daughter a little less stressful and less financially stressful. Granted the special needs community does benefit from the programs, it doesn't even begin to cover everything that they may need. I honestly do not k ow how I would have been able to stay in my home with her if I didn't have the opportunity to become her home help provider and be paid. However, i don't think there is enough programs for the familied that choose to have their loved ones live with them. Not enough programs or

funding for these programs for individuals past the age of 18yrs old. A lot of times special nerds do not change once someone turns 18yrs old. In my experience it felt like there is all this help for your special need loved one only if they are under a certain age. After they age out of the school system at 26yrs, its like the special needs community is pushed to the back, forgotten about. As if they were saying that you don't have much else to contribute to society after you age out of the school system. So the programs that are available have made my daughters life ok after aging out of the school system but more needs to be done to ensure these individuals are valued at ANY age. After my daughter turned 26yrs old, a lot of her services went away because she wasn't in school or she was too old for programs. For instance, i had no clue that she could have had Childrens Special Health Care Services for a few more years. By the time i found this out, she was a few months from the programs cut off age. These programs for what they do help with, allows my daughter to live with dignity and feel safe at home with her family.
If we didn't have these programs It would make it extremely hard to properly care for my daughter. A lot of the financial responsibility would fall on the family. What medicaid covers for her doesn't even begin to touch on what she truly needs. Like whomever is making these decisions on what to cover and not to cover, does so by drawing a decision out of a hat. Not based on actual need, making us fight for months sometimes years to get something covered only to be told you need a new script for whatever you were trying to get covered. It needs to be made easier to get items covered. Especially the way they decide which meds to cover and not cover. Some individuals cannot afford their life saving medicines or they can only take certain kinds. If these programs were to completely go away, there would be so much more poverty and neglect (by no ones fault of their family) because we couldn't get the proper services to take care of our loved ones. The special needs(a blanket term to encompass all types of disabilities) community is A LOT bigger than you even can begin to realize. Not having these programs i feel would increase mental health issues in caregivers because of the added financial stressors and because of the feeling of being ignored and bring made to feel even less important than now. Honestly it feels at times i get told well tough cookies (but in a much less nicer words) you're on your own, we don't care if your loved one is an adult. When programs go away like this, it gives a feeling like they dion expect the special needs community to live past adulthood. My local county has done away with the only program that would have helped my daughter transition from going to school everyday to not being able to do much of anything because of no services. It was the day program for the special needs community that allowed them to be more integrated within the community they live in. I use to see special needs community all the time. Now im lucky if i even see them anymore unless their families take them out. This program i feel helped the not special needs how to act, to accept and not be afraid of the SN community and to show them that just because they're SN, doesn't mean they don't have anything left to contribute. Also it needs to be more inclusive in terms of the programs that is out there. EVERY SINGLE PROGRAM i have tried to get my daughter into had turned me away because they do not have the staff to care for my daughter. They rather can take care of more able bodied special needs individuals. So what is the purpose of these programs if they cannot serve the whole special needs community?

Ivy Bivins, Detroit, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because.

Terri Teamer, Clinton Township, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because I live alone and my children are not close to me! I am 71 with Lupus, Fibromyalgia and COPS! I drive when I can, but since I have a tendency to pass out I stay home. If there were no organizations to help we seniors would be in trouble!

Kaitlin Grant, Lansing, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because I have seen the direct impact that it has on people with disabilities and older adults. As someone who has worked at a local Community Mental Health agency as a developmental disability case manager and at an Area Agency on Aging, I can attest that the individuals who had the opportunity to live in the community had much better outcomes than those who were forced into a nursing home because of their financial situation. It is hard to explain the heartbreak that I saw when I had to tell people that their only option to receive the care they need was to remove them from their community living arrangement and place them into a long term care facility. The clients I worked with had friends and support in the community, they were able to participate in activities they care about and be a part of something. When that was taken away from them they felt they had nothing left; no reason to continue living. Choice is what matters most in ensuring people can live a meaningful life and I believe that HCBS is vital in ensuring that choice.

Kimberly Lifton, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because my stepson, Benjamin Hirsch, has thrived since moving into a "pod," affiliated with JARC in Michigan. He is 29, cognitively impaired, and illiterate. He has both intellectual and neurological deficits that make it impossible for him to enjoy complete independence. But because of these benefits and services (hours for caregiving, social activities, and Medicaid), Ben and his roommate (who is autistic) qualify for 24-support

services that afford them the independence they need to feel valued in the community where they both live.

Ben also has a job. He was trained by Project Search, which help young persons with intellectual and developmental disabilities secure competitive employment. He works 20 hours a week delivering and sorting linens at Henry Ford Health Systems in West Bloomfield, MI.

I must say, Ben is one of the happiest humans I have ever known -- much of this is due to the independence he feels by living in his own apartment and going to work five days a week.

Programs like Medicaid HCBS are essential and make a difference in Ben's life and so many others' lives. If he did not have these programs, he would not have trained caregivers supporting him, teaching him life skills, because it would be prohibitive without assistance from these programs. He would lose the feeling of independence as well because we would not be able to afford to support him in an apartment and also pay for 24-hour care. Most people would not. His care, even with community-based services, costs our family nearly $3000 per month. I don't want to even think about what might happen without Medicaid HCBS.

Ben works so hard. He is a productive member of society. He is thriving on his own. He and every human with any disability deserves support from this great country.

Roger Roper, Ypsilanti, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because For me, community is more than just a collection of people living or working near each other—it is the heartbeat that makes life meaningful, especially for someone like me who navigates the world with a disability. Being a disabled American often means facing barriers that others may not see: inaccessible spaces, assumptions about what I can or cannot do, and the constant need to prove that I am capable and deserving of the same opportunities as anyone else. In these moments, community becomes not just a comfort but a necessity.

Community is the people who notice when I need support without me having to ask, who celebrate my accomplishments at work, and who offer patience and understanding when challenges arise. It’s the coworkers who respect my abilities and provide a space where I can thrive, the neighbors who lend a helping hand without hesitation, and the friends who check in simply because they care. These connections, no matter how small they may seem to others, are profoundly sustaining.

But community is also more than support—it's encouragement, reassurance, and a shared sense of purpose. It reminds me that my daily efforts, the work I put in, and the contributions I make are seen and valued. Even on days when I feel exhausted, overwhelmed, or frustrated by accessibility hurdles, community whispers to me: "You belong here. Your presence matters. Keep going." There is a gentle strength in that knowledge, a warmth that makes life feel a little lighter.

For someone like me, who goes to work every day, community is both practical and deeply personal. It's the systems that allow me to do my job effectively, the colleagues who treat me as an equal, and the small acts of inclusion that affirm my dignity. But it's also the unspoken understanding, the smiles, the check-ins, and the moments when someone simply says, "We've got you." That is the kind of community that sustains me—not just physically, but emotionally, mentally, and spiritually.

In short, community is about connection, reciprocity, and belonging. It's about giving support and receiving it, advocating for accessibility, and creating spaces where everyone—regardless of ability—can participate fully. It's a lifeline, a reminder, and a source of strength. And if you take a moment to look closely, you might see that building this kind of community doesn't just help people like me—it enriches everyone, because a truly inclusive community is stronger, kinder, and more resilient.

Linda Greenhill, Trenton, Michigan

Dear Members of the Special Committee on Aging,

It's awful what's happening groceries are higher My rent went way up and clothes are expensive even dog food. This is freaking ridiculous Tell Trump to leave office. I mean I know that's no possibility but something has to be done to get this idiot out of office. He's hurting the US citizens

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Geneva Taverbaugh, Flint, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because, I am on a fixed income. I'm 61, became disabled in 2012, Medicaid was great when I became disabled because it covered my 20% that Medicare would not cover. This year 2025 I was told that I will no longer receive the full coverage but just to cover medicine. I have labs, test and I found out I have a blockage and have to take more test at a hour away hospital. It will not be covered, I have to pay $4000. I thought Medicare would pay at least 80%, but it was totally denied. Where I live (in Flint) the equipment isn't reliable,

therefore my heart doctor sent me to a bigger hospital to take test. I am going to a different insurance that will accept me being able to take test for treating my heart. I know I would need a stint but how can I get one of both Medicare and Medicaid will not pay.

Marianne Paskiewicz, Grand Rapids, Michigan

Dear Members of the Special Committee on Aging,

Community living matters to me because I am 67 years old and I use a cane or a walker. Having more accessible housing for low income Seniors and Disabled people living on Social Security is crucial.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Minnesota

Mary Wallin, Willmar, Minnesota

Dear Members of the Special Committee on Aging,

Community living matters to me because I have lived here all my life.

Leon Saeland, Bemidji, Minnesota

Dear Members of the Special Committee on Aging,

being part of the community helps me feel less alone. I also feel that being in the community helps raise awareness on accessibility for everyone. Being able to stay home and part of the community helps me stay healthy. having access to HBCS Allows different options so I can say home and be part of the community. Each program has its place of importance. I feel like if you take away any piece it would be impossible for people with disabilities to live at home.

Maryjo Bartos, Eveleth, Minnesota

Dear Members of the Special Committee on Aging,

Community living matters to me because I work in a group home they have Medicaid if that gets cut they can't go appointments if need be or get there medications.

Chris Higgins, Rochester, Minnesota

Dear Members of the Special Committee on Aging,

Community living matters to me because I get to live my life the way I want to. Please don't change that. Thank you

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Peggy Erickson, Minneapolis, Minnesota

Dear Members of the Special Committee on Aging,

Community living matters to me because housing is at Mega premium. Costs are astronomical!!! Older population are hit hardest, & require places to call home.

Susan Eisenbacher, Cambridge, Minnesota

Dear Members of the Special Committee on Aging,

Community living matters to me because my dear mentally handicapped brother lived in a RSI community based group home in Princeton MN. He was able to attend the local county fair, attend local airport annual pancake fund raiser, visit the local exercise facility, hike around the local parks with me or staff members. Some of the other residents worked at local businesses. His life was a struggle but due to community based services he was a happy camper.
Thanks for your time and consideration.

Kathleen Schaffenberger, Eagan, Minnesota

Dear Members of the Special Committee on Aging,

Community living matters to me because our daughter is disabled and she is currently living in an apartment. We are so grateful about the care she receives in the community. SNAP Benefits give her the much needed food that she needs daily. She is able to see doctors, specialists, therapists, go to appointments through Lyft and medical rides, and Social Security provides monthly payments so she can live in her apartment. We are very very grateful that she can do her best and enjoy her life with her benefits. Thank You.

Richard Grimm, Minneapolis, Minnesota

Dear Members of the Special Committee on Aging,

Community living matters to me because

Myrna Peterson, Grand Rapids, Minnesota

Dear Members of the Special Committee on Aging,

Community living matters to me because I was in an auto accident 30 years ago, which resulted in a C345 incomplete fracture of my spine! To date, I have had 42 procedures to assist me in the quality of life I have today. I still suffer from chronic nerve pain from my chin to the tip of my fingers and toes. The first 10 years I was medicated heavily with narcotics which did nothing to ease my pain, but kept me solely in the dark from reality. In the last 20 years since I experienced help from a rehab center to get rid of the narcotics within my system, my quality of life as a quadriplegic has been a struggle still. There is so much need for accessibility within my community, my state and throughout the nation. The ADA standards are not enforced and if you do not have a different ability, generally, you are not even aware of how inaccessible your community is. I serve on several local, state and national boards to advocate for better

accessibility. 10 years ago I also started my own nonprofit called Mobility Mania - Accessibility for All. I believe that it is every individual's right to have quality of life opportunities in spite of their age, ability, cultural difference, or financial status. It is vital to the survival of those of us who live life differently for legislators to do the right thing and enforce the ADA standards to their fullest and go beyond to make them friendly standards, as well. It is discriminatory for anyone to hold an event that is not capable of providing accessibility for mobility, visually, hearing impaired and cognitively challenged people.

Jolie Klarich, Cambridge, Minnesota

Dear Members of the Special Committee on Aging,

Community living matters to me because I am quadriplegic.

Raleigh Koritz, Minneapolis, Minnesota

Dear Members of the Special Committee on Aging,

Because I care!

Melissa Kubiszewski, Saint Paul, Minnesota

Dear Members of the Special Committee on Aging,

Community living matters to me because I need low income based housing and I want to be with my community and enjoy life with my community. I want to be independent as well.

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Statements from Mississippi

Susan Abdullah, Tylertown, Mississippi

Dear Members of the Special Committee on Aging,

Community living matters to me because without assistance, so many individuals are left without the ability to see the doctors, have enough food, or even just have the dignity that is deserved by living indipendently. Please help.

Mary Gilly, Moss Point, Mississippi

Dear Members of the Special Committee on Aging,

Community living matters to me because my oldest son has Down Syndrome. He functions on a 5 to 6 year old level. He is able to have the support he needs to have a part time job, go shopping, participate in community activities and participate in a special needs bowling team.He doesn't have to depend on us for these activities.
He is employed as a baker and custodian at the Finest Grind Coffee Shop in Ocean Springs, Ms. Yes, he bakes. His job coach provides assistance with reading recipes, measuring and staying on task. He gets to meet new people and make friends. The best part of all this is that he doesn't have to have his mama and daddy with him all the time. He is very proud of what he can do and that he can earn a paycheck just like everyone else.

He will always need someone with him at home, in the community and at home. We will take care of him at home as long as we are able. However, since he is in his mid forties and we are in our mid seventies we know that he will need someone to be here for him in the future. He does have a younger brother who lives in another state who would try to care for him in the future, but this would require our son, Nathan to move there. Nathan would lose his Medicaid Waiver support. His younger brother is not in the financial position to provide the supports Nathan needs to continue function in society in a different state. There is currently a 12 year waiting list for the ID/DD Waiver in Mississippi. I have no idea what the waiting list is for Louisiana at this time.

Ideally, Nathan would be able to stay in his home in his community with support. He would need someone to be in the home with him when he's there. The group homes in our area are rather grim. Nursing homes and institutions are more expensive. He would lose privacy and independence without the support he gets from Medicaid ID/DD Waiver.

Thomas Watson, Byram, Mississippi

Dear Members of the Special Committee on Aging,

Medicaid Home and Community-Based Services (HCBS) have helped me to live in the community and avoid a nursing home for about the last 25 years. Because of these services, I've been able to pursue a college education and a job. Without these services, I would not be able to contribute back to society by working and paying taxes, nor would I be involved in the community. This program affords me the opportunity not only to work and to contribute but also to attend church and other social functions, since I have a severe disability that confines me to a wheelchair, and I need assistance at all times from people who are trained to help me, including feeding me, repositioning me in my wheelchair, washing my face, and all other activities of daily living. As a 37 year old with a single mother who is almost 70, this is extremely important, as she would not be able to do it all on her own, especially considering that my brother has the same genetic condition and also relies on HCBS services.

Roy Watson, Byram, Mississippi

Dear Members of the Special Committee on Aging,

Community living matters to me because I rely on it every day to live and work. Despite the fact that I'm 40-years old and can only barely move my fingers, I'm able to live at home and work with a NASA contractor remotely. If not for my team of caregivers that I access thanks to HCBS programs, I'd end up in a nursing home, unable to work and pay taxes, while using even more taxpayer dollars.

These programs are essential. And we need federal access and eligibility. Right now I'm a prisoner to my state because my critical HCBS to not travel with me. In the modern world, where college is essential and good jobs sometimes require relocating, we need reliable, uninterrupted, nationwide access to these programs no matter where we happen be.

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Statements from Missouri

Barbara Inman, St. Louis, Missouri

Dear Members of the Special Committee on Aging,

"My 25th Re-Birthday — A Story of Falling, Faith, and Raising"
God has been carrying me for twenty-five years this month.

On September 29th, 2000, I left home as a single mom to go to work. In one instant my world changed. I fell twenty-five feet down an empty elevator shaft and landed on a concrete floor strewn with glass, cans, and debris.

When you meet me now you might think you know my story — you see a smile, a friendly face, a woman who tries to be warm and courteous. But on the inside I am very different than you might imagine. That fall did not just bruise and damage my body; it rearranged my life. It took my sense of certainty, it took pieces of the person I used to be, and it pressed me into a new form of living.

In the years that followed, I went through more than forty surgeries. Lost everything I worked so hard for. I faced pain and setbacks that most people never see. I now live with a frontal-lobe traumatic brain injury — a TBI — that has changed the way I think, feel, and do life. Many of my disabilities are invisible. You can't always see the anxiety. You can't always see the depression. You can't always see how hard a simple decision can be when your brain is still relearning how to be your friend.

There were so many times I wanted to give up. When you suffer long enough, your soul grows weary — and I know that weary place. I was confused, scared, tired and lost for a very long time, and still have that feeling. I could not find the light through the darkness that surrounded me.

But my story is not only about the fall or the suffering. It is about what God did in the hole where I thought I would stay. It is about the hand that reached down and lifted me out. I had to drag myself out of that abyss time and time again. I had to relearn how to walk and talk at a Brain Injury center (St. Johns HIRC) for over a year and lived in Assistant Living for 7 years suffering more abuse, lost my children which was the worst, lost my home, almost everything I had, it wasn't the suffering that defined me — it was the way I kept rising. That relentless, stubborn insistence to keep going, to keep growing, to keep believing — that is what formed me.

Scripture says in Isaiah 43:2, "When you pass through the waters, I will be with you; and when you walk through the fire, you will not be burned." That promise became real to me. I walked through fires —been through over 40 surgeries, grief, and long dark nights — and I was not consumed. God carried me when I could not carry myself.

I didn't become brave because I wanted to be brave. I became brave because there was no other option. God made me courageous out of necessity, and He made me more than the things that would have defeated me. I am not just a survivor; I am a warrior with an iron will and a passionate spirit. My scars are not signs of shame — they are maps of God's mercy. They tell the story of battles fought and won through the strength He supplies.

There was a season I felt ashamed — ashamed that I had fallen, ashamed of being different, scared people would not accept me. But today I celebrate those differences. I celebrate my cracks because the light comes through them. I celebrate the invisible wounds because they show His handiwork in restoration. I will celebrate my 25th "rebirthday" today September 29th. The day I fell was the end of one life and the beginning of another — a life shaped by grace and sustained by God.

Romans 8:28 says, "And we know that for those who love God all things work together for good." I cannot explain every painful detail, but I can say with my whole heart that God took what was meant for ruin and made a purpose. He has used my broken pieces to reflect His strength and His love.

So if you see me and think you know me — think again. Don't measure me only by what is visible. Pray for me when I am weak. Walk beside the hurting. Speak gently to the ones whose struggles are hidden. And if anyone here is carrying a secret burden — whether it's a physical wound, a broken heart, or a mind that is tired — know this: God sees you. He does not forget you. He can lift you out. He turned my fall into a rebirth.

Today when I celebrate my 25th rebirthday, I do not ask for pity. I only ask that my story point to the God who carried me, who heals in ways we sometimes don't understand, and who gives us strength one day at a time.

My Closing Scripture & Prayer

Let us be reminded of Psalm 34:18 — "The Lord is close to the brokenhearted and saves those who are crushed in spirit."

Dear Heavenly Father, I thank You for carrying me when I could not walk or talk. I thank You for every surgeon's steady hand in over 40 surgeries, every prayer lifted on my behalf, and every small victory that proved Your faithfulness. Continue to use my life to point others to You. Heal the hidden wounds in this room. Give strength to the weary and hope to the hopeless. In Jesus' name, Amen.

Susan Stuart, Otto, Missouri

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a person with a severely-challenged immune system who has had to infuse donor antibodies weekly for about 15 years in order to stay alive. I am almost 60, and cannot imagine what it would be like to lose my disability. I have fought so hard to keep existing. Please fight for my right to live.

Carolynsue Alflen, Fair Grove, Missouri

Dear Members of the Special Committee on Aging,

HCBS is an important to me because I am disabled, older, DeafBlind constituent of USA. Please urge to support HCBS. That does helping and educating many things to qualities of lives of us.

Jane Markley, Festus, Missouri

Dear Members of the Special Committee on Aging,

Community living matters to me because we all have to share this planet and the sooner we work together the better.

Patricia Reed, O'Fallon, Missouri

Dear Members of the Special Committee on Aging,

Community living matters to me because I had a sister who benefitted from these programs. She was mentally challenged. She went to a state school till she was 21. Then she worked at a workshop for people with disabilities till she was in her 50's. She also stared living in a group home when in her 40's. She really liked the group home & working at a workshop where she made some money. I think she had a pretty good life & she seemed happy. She passed away when she was 70. Without the help of Medicare & other programs this would not have been possible. This is a good idea for people with disabilities. I was her guardian so I was very aware of the benefits that she received. Thank you.

Debra Barcus, Maryville, Missouri

Dear Members of the Special Committee on Aging,

Community living matters to I AM A SENIOR CITIZEN IM 70. I LIVE ON SS DISABILITY. I WAS FORCED TO BE DISABILITY. I HAVE MOBILITY ISSUES. HAD MANY MSNY SURGERIES ON MY HIPS BILATERAL N KNEES BILATERAL. I ALSO HAVE INSTINE ISSUES N GET BOWEL BLOCKAGES N HSVE TO MAKE MANY TRIPS TO THE HOSPITAL. I PAY MY RENT N BILLS. THEN I HAVE TO DECIDE ???? DO I BUY MY BABY (DOG) FOOD, OR MEDICATIONS

Carol Kilburn, Willard, Missouri

Dear Members of the Special Committee on Aging,

Community living matters to me because my granddaughter has down syndrome so she will need some help from the Ark in Springfield MO please don't look past them look at them and let them know that they all matter to you and our community

---

Tracey Hermann, Old Monroe, Missouri

Dear Members of the Special Committee on Aging,

Community living matters to me because my 28 year old son with severe autism, static encephalopathy and epilepsy enjoys being around his peers. He loves his Adult Day Program where he participates in activities and volunteers with Meals on Wheels. The staff is amazing and it allows me to work as a substitute teacher. He's been going there since he aged out of school at 21 years old. We can't imagine what we would do without this service!

Nicole Noblet, Kansas City, Missouri

Dear Members of the Special Committee on Aging,

Community living matters to me because without Medicaid Home and Community Based Services I would be in a hospital. Being able to live at home with my mom means I can have a dog and it means I can have a job that I love, helping others with developmental disabilities. Everyone with a disability deserves to be a part of their community. Community living is less expensive than institutions, and it's the right thing to do.

Alysha Broughton, Florissant, Missouri

Dear Members of the Special Committee on Aging,

Community living matters to me because I am one of three registered and licensed dietitians and nutritionists in the state of Missouri who work explicitly with people with intellectual and developmental disabilities. I have seen firsthand that having the nutrition services has increased the quality and enjoyment of their lives.

Paula Evans, Dexter, Missouri

Dear Members of the Special Committee on Aging,

Community living matters to me because I had been receiving help with Home Health but was recently stopped because I became eligible for Medicare but I still have Medicaid. The home health care company stopped my services all together. I require 72 hours a month, 7 days a weeks, 3 hours a day and for the past 2 months I've not had a homemaker here to help me to eat, bathe, dress, move about the home. Someone needs to help me with this issue as being disabled I can't do it on my own.

U.S. Senate Special Committee on Aging

"Aging in Place: The Impact of Community During the Holidays"

December 3, 2025

Statements for the Record

Statements from Montana

K.G.H. Nicholes, Montana

Dear Members of the Special Committee on Aging,

I have lived in a wonderful place, where I own my home, for 35 years. It is quiet here and I can see the stars at night. It's a ghost town - there are no stores, no public transportation, no local services. I'm getting older, and trying to figure out how to find someone to help my household on a regular basis. Social security is not generous, so I can't offer much pay. I'm hoping I can mentor, and offer room and board to someone who wants to live in an isolated quiet place.

Jeremy Brooks, Bozeman, Montana

Dear Members of the Special Committee on Aging,

Community living matters to me because they are very important to me and help me out whenever I need it.

Deidrie Leaf, Missoula, Montana

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a mother of a son with autism with learning disabilities. I have been my sons advocate for his diagnosis his whole life. After being diagnosed at 3 years of age, I was able to enroll my son into preschool with disabilities. Helping my son with these tools at early age was what I know now, was much needed. It helped my son navigate a world that was not made for him. He dealt with sensory issues and so we as a family with his pediatricians help put him into speech therapy. My son at that point in his life was non verbal. Then from there his speech therapist referred my son to OT therapy for eating disorder. My son's sensory issues was affecting his ability to eat. Without these tools my son would have had no help. Which would of left me with absolutely no help in this disability. With intense speech, and OT therapy this helped my son and myself through life. My son at age 5 spoke for the first time not just gibberish ..he said mom. With his sensory issues At 11 he started to eat meat finally and not just chicken nuggets. Without all these therapies and his IEP he is getting through life and understanding his autism. My son's sensory issues are still there but we have the tools to help him and he knows the tools also to help himself. He is 16 years now and he is finally reading. At grade 5 in his IEP meeting we were told my son was never going to read. I have never felt so defeated in my life and left in tears. My son my have autism but I wasn't going to let it define him. I was then having a conversation with his special ed teacher and he said "let's try a new way of reading for JJ."
Memory!! We stopped phonics and tried using his memory on the shape of the word. It took two

years but I did it! My son is reading has a little bit of a hard time sometimes…but he is reading! We are trying to teach him now how to write. Without all these tools in our lives would my son have gotten this far?

My goal for my son is that he learns to write and with the help of his IEP and his OT therapy we can meet that goal. My son is one of the smartest people I have ever known. His brain is just wired differently and that's all. I know my son will need help throughout his life. I had a conversation with his middle school teacher and I asked do you think my son will ever be able to live on his own…

She replied "no…I feel he will need help his whole life."

I asked her this because I, JJs mother was diagnosed with cancer and I have now progressed to stage 4. I'm doing better and have been taken off immunotherapy for 5 months. Only to see if the cancer was going to stay NED I will never be in remission. So I need to know that my son will be okay when and if I leave him early in life. I need to know my son will be okay on his own because without these services he will be dealing with this alone. I'm his caretaker and without OT therapy we were at a hard place. My son needed help toileting till 13. So his IEP and OT were my saving grace for me and JJ. These are all sensory issues that he deals with. He also deals with anxiety as all kids with autism do. This world has many sounds that almost feel like they almost physically hurt him.

Im proud to say my son is wearing just his hat and no noise canceling headphones; which he use to wear every minute of the day. With all these supports and tools he is learning, he is learning to live in this world.

His reading has been huge!! He is seeing a whole new world through the books he is reading. My goal is writing and with the help of OT and his IEP we will meet that goal even if it takes years. He will go to college with support. This is my dream. I look back and wonder were we would be if we didn't have these services.

And as a grandmother I have a 5 year old grandson diagnosed with Autism. He is non verbal. This was his first year of school and he is saying words. I only hope these services will be available for him also in the future.

U.S. Senate Special Committee on Aging

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December 3, 2025

Statements for the Record

Statements from Newbraska

Donna Hauck, Scottsbluff, Nebraska

Dear Members of the Special Committee on Aging,

Community living matters to me because everyone deserves to live a full life no matter who you are.

William Mathies, Mccook, Nebraska

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a son who needs these services, please continue to help the one who can not help them self's

---

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Nevada

Charlene Boydston, Pahrump, Nevada

Dear Members of the Special Committee on Aging,

Community living matters to me because It takes care/helps, of ALL the people who live there!

Gregory Pavlidis, Henderson, Nevada

Dear Members of the Special Committee on Aging,

Community living matters to me becauseit is the right thing to do, to care for those, who cannot care for themselves...

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from New Hampshire

Linda Ferland, Claremont, New Hampshire

Dear Members of the Special Committee on Aging,

I know people who've been affected badly, by no access to SNAP & the Medicaid Cuts have left so many without enough coverage for healthcare they need to keep going--in these horrific presidential rulings.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from New Jersey

DISABILITY RIGHTS NEW JERSEY

ADVANCING JUSTICE. ADVOCATING INCLUSION.

GWEN ORLOWSKI, EXECUTIVE DIRECTOR

Submitted Written Testimony From
Disability Rights New Jersey For
The Senate Special Committee On Aging Hearing On
Aging in Place: The Impact of Community during the Holidays
December 8th, 2025

Chairman Scott, Ranking Member Gillibrand, and other members of the committee, thank you for convening this hearing on an issue that is critical to New Jerseyans with disabilities and older adults. Community is where New Jerseyans want to live, access services, work, learn, and participate fully in all aspects of society.

Disability Rights New Jersey (Disability Rights NJ) is the federally funded, non-profit organization designated as the Protection and Advocacy system for people with disabilities in the State of New Jersey. We advance the human, civil, and legal rights of people with disabilities and promote their self-determination, independence, productivity, and integration into all facets of community life.

Community inclusion is essential for New Jerseyans with disabilities and older adults because:

- It reduces isolation which lowers the risk of abuse, neglect, and financial exploitation;
- It ensures access to tailored resources and services while promoting awareness of rights, and
- It fosters shared experiences, peer support, and a sense of belonging through inclusive activities that encourage engagement and participation.

Disability Rights NJ advocates for all aspects of community living: education, accessible housing, employment, and transportation, and ensures services are delivered in the most appropriate integrated setting. Disability Rights NJ collaborates with organizations such as the NJ Council on Developmental Disabilities, the Boggs Center on Disability and Human Development, Independent Living Centers, New Jersey Long-Term Care Ombudsman, and other non-profit organizations to achieve a society where New Jerseyans with disabilities are fully included and recognized as integral members of their communities.

This year, we interviewed individuals with disabilities about how home and community-based services allow them to live a fulfilling life in their community. We have gathered

210 SOUTH BROAD STREET, 3RD FLOOR,
TRENTON, NEW JERSEY 08608
DISABILITYRIGHTSNJ.ORG
ADVOCATE@DISABILITYRIGHTSNJ.ORG
800.922.7233 | 609.292.9742
609.633.7106 (TTY) | 609.777.0187 (FAX)

their stories in a video which you can watch at https://www.youtube.com/watch?v=UYZWZ1U4G1Q.

Dave is an individual with many disabilities and resides in an assisted living facility in Atlantic City. His care is funded through Medicaid, and he is able to enjoy his life on the Boardwalk knowing that his medication and health care needs are met through Medicaid. Without the supports and services that he receives in his assisted living facility, he would be unable to live independently.

Robert is a 68-year-old individual with autism and scleroderma. He currently resides in an assisted living facility in Warren, New Jersey, where he has resided for many years. He requires assistance with activities of daily living such as getting out of bed, getting dressed, and providing him his medications. The care he receives allows him to enjoy activities such as watching tv and listening to music in his own private space.

Joan resides in an independent apartment in Princeton, New Jersey. Because of her disabilities, she needs assistance with activities of daily living. She has aides come to her apartment and assist her with cleaning. They help her transfer while sitting. They assist her if she is not feeling well. Without these caregivers, she would not be able to continue to live independently in her apartment.

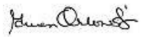
These are just a few examples of how Medicaid's home and community-based services allow individuals with disabilities and older adults maintain their independence and live their lives in their communities.

Community inclusion is not just a goal, it is a right and a necessity. Disability Rights NJ is at the forefront of ensuring these rights are realized across all areas of life: education, employment, housing, transportation, healthcare, etc. We work every day to make sure that New Jerseyans with disabilities and older adults can live with dignity, independence, and fully participate in society.

We appreciate the committee's attention to this issue and look forward to continuing our work together to build a society where inclusion is not just an aspiration, but a reality for all. Should you have any questions, please feel free to reach out to Mary Ciccone at mciccone@disabilityrightsnj.org.

Sincerely,

DISABILITY RIGHTS NEW JERSEY



By: Gwen Orlowski, Executive Director

To Whom It May Concern,

My story is a long one, filled with trials and tribulations. When I was a child, I was diagnosed with a condition known as Phenylketonuria or PKU. PKU is an amino acid disorder that, if left untreated, may cause seizures, hyperactivity, eczema, and intellectual disabilities. When my parents first found out about my disability, the doctor recommended that I be institutionalized. While visiting one of the prospective institutions, an aide pointed across the street to a cemetery and said, “That’s where the ones go that don’t make it.” Once hearing this, my parents decided they were going to go against the doctor’s orders and would become my advocates. They raised me to be as independent as possible and taught me the importance of advocating for myself.

As an adult, I have made it my life’s mission to advocate for not only myself but others as well. I am an active member of the Knights of Columbus, president of the Arc Angels, and an active advocate in my community. I am extremely well versed in my rights and have no problem speaking out about something that I feel is unjust.

As I have gotten older, I have had to transition to a supportive living program. The staff here are incredible, and they provide me with all the assistance I need while also giving me the space to be independent. Some tasks the staff help me with include driving, food shopping, clarifying important information, signing any forms I need, and many other daily necessities. If it weren’t for places like this, I would be unable to thrive in our society. Being part of these communities has allowed me to not only exist in this world but has allowed me to conquer the world. Taking away these aids would be a huge slap in the face to people with disabilities everywhere.

I sincerely hope these agencies continue to be available to people who truly need them. These agencies truly do make a world of difference in people’s lives, including my own. I am passing my knowledge down to the younger generation, so they too are informed of their rights and can advocate for their community. We are building a movement together, and we will fight to keep these programs in place and will continue to fight for our rights.

Sincerely,

Bill Byrne

December 8, 2025

To the Senate Special Committee on Aging:

I have worked with many clients who have thrived in situations where home and community-based services (HCBS) were available to them through New Jersey's Medicaid program. New Jersey provides HCBS in several settings, including assisted living facilities, in homes and apartments, through adult day care coverage, and working with numerous providers in the residential programming space for the developmentally disabled and those with traumatic brain injuries. These services are critical to enrollees.

Many of my clients live in assisted living facilities, and the presence of affordable waiver services that can be taken advantage of in an assisted living facility after private funds run out create enormous peace of mind. I have had assisted living clients who were siblings or parent and child as well, living in side-by-side units or shared spaces, each with unique needs that could be served together in a pleasant environment integrated into the community at large. This is a program in New Jersey that I especially think works well.

I have also seen caregivers given respite through their loved ones attending adult day care in the community several days a week. It was very difficult for caregivers when adult day was shut down during COVID and only made me realize how vital a service adult day care can be to prevent caregiver burnout and allow robust social interactions for the enrollee.

I have had clients who relied upon Medicaid caregiving in their house. One client of mine has been paralyzed for over a decade and relies upon both private duty nursing and home health. These services, which include feeding, drinking with supervision to guard against aspiration, stretching therapies, and full assistance with all activities of daily living are literally the difference between this young man's life and death. I have seen his hours be cut back, added to and then cut back again, and the stress on his parents as primary caregivers and coordinators of services is immense. I truly believe that if he had to go to an institution, his life expectancy would be curtailed.

I have had clients who hired family members to be their in-home caregivers. In one situation I recall, the family member was providing this care at no cost prior to enrollment in the self-directed program, and she had intimate knowledge of the enrollee and the trust of that enrollee. Paying that family member was both life-changing for the enrollee to have a trusted caregiver who now had supervision and support of a fiscal intermediary and the family member acquired needed pay for a job well done and additional skill enhancement provided by Medicaid. Eventually, the family member sought out official licensure as a home health aide so as to work with other people in a community-based setting.

I hope this information is helpful, and I would be happy to answer any questions. Thank you.

Sincerely,

Lauren S. Marinaro, Esq.
Partner | Masters of Law and Letters in Elder Law
Fink Rosner Ershow-Levenberg Marinaro, LLC
Clark, NJ

Mary Farley, Springfield, New Jersey

Dear Members of the Special Committee on Aging,

Community living matters to me because my son James is 33 and We pray everyday that congress will help us with a different situation when it comes to living independently. It takes a village. I think the reality of the world congress or anyone else doesn't no until it becomes your everyday life. I would be most grateful If I am able to tell how are needs can not be met. James , 3 years ago asked for help for counseling through DDD I got it for him. My case manager, and The Phycologist and myself are still shocked never got a call for him to be heard. I know that is suppose too be a happy letter. I think in reality housing need another level for some like James. Looking forward for the right person to get to me. Thank You Mary Ann Farley.

Sister Miller, Newark, New Jersey

Dear Members of the Special Committee on Aging,

Community living matters to me because

Please help us

Sandy Smith, Lawrence Township, New Jersey

Dear Members of the Special Committee on Aging,

Community living matters to me because my son can live in a supervised apartment with two other young men with disabilities. It is critical that he has housing and care because his parents are elderly and he has no other family. He also benefits from job training and placement services.

Robert Albert, Tinton Falls, New Jersey

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps each other get through this cold world. We’re all here for each other

---

Lori Leopardi, Ewing Township, New Jersey

Dear Members of the Special Committee on Aging,

Community living matters to me because having a diverse population creates opportunities for growth for the disabled and non disabled alike. People with disabilities need access to resources and experiences that enrich their lives. Those of us fortunate enough to not experience a disability are able to interact with and develop empathy for people with differing abilities.

"You ultimately judge the civility of a society not by how it treats the rich, the powerful... but by how it treats the poor, the disfavored and the disadvantaged," Bryan Stevenson.

Do what's right. Save lives by saving Medicaid and HCBS.

Ann Sandritter, Old Bridge, New Jersey

Dear Members of the Special Committee on Aging,

Community living matters to me because I like being a decent person.

Raffaella Selvaggio, Wallington, New Jersey

Dear Members of the Special Committee on Aging,

Community living matters to me because we need our government to step up and take care of our Country and all the people in it struggling every day to survive. LETS MAKE AMERICA GREAT AGAIN!!!

Madeleine Lee, Westfield, New Jersey

Dear Members of the Special Committee on Aging,

Community living matters to me because
People with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. HCBS help make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.

Jessica Letts, Neptune City, New Jersey

Dear Members of the Special Committee on Aging,

If I don't have the services that receive then I can't attend day program's which I really enjoy doing. I don't want to lose my programs or my friends from the programs please don't the services away

---

Marisa Anderson, Old Bridge, New Jersey

Dear Members of the Special Committee on Aging,

Community living matters to me because living in a loving home is essential for this population. They are in a caring, well-maintained environment. Living in a group home can sometimes be unsafe, unhealthy, and lonely.
More pay, better training, and cameras may resolve this issue

---

Carl Major, Gloucester Township, New Jersey

Dear Members of the Special Committee on Aging,

Community living matters to me because.

Pamela Ginet, Ocean City, New Jersey

Dear Members of the Special Committee on Aging,

My oldest son is 25 years old and has Down syndrome, autism & a seizure disorder. Community living is important to us because we rely on Medicaid and the associated programs to help facilitate his independence and community inclusion. While he doesn't live the typical life of a typical 25 year old, we do our best to build a program and schedule with his Medicaid funding that provides enriching activities, community outings, social interactions, therapeutic activities and more. He is not capable of doing any of these things independently so without the support of Medicaid funding we would not be able to provide him the supports to be successful in the community. The cost to keep him in the community is much less than the cost of placing him in a group home and the quality of life is so much better when he can live in his community with his family. Please continue to support individuals with disabilities and help them maintain the dignified life of living in the community.

Sarah Adam, Philipsburg, New Jersey

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps me and others who really need it, I need help with my house and I'm my community there is no money too help me fix my house, we really

need your help too save our homes and too help people like me with disability! Thank You for your Time! Sarah Adam

---

David Owens, Vineland, New Jersey

Dear Members of the Special Committee on Aging,

I would like to have some subsidies for the purchase of a van to transport me for medical reasons. If I were to use a handicap transport. Every time and applied for insurance coverage it would be a lot of money. I have my own van I am paying on and it's making it tight to live on. My van needs $2000 worth of repairs, which I can't afford now.

Barbara Gainsford, Gloucester Township, New Jersey

Dear Members of the Special Committee on Aging,

Home and community resources are so valuable to disabled individuals and those who are aging. We all know someone who needs these services.

Jaszmene Smith, Bridgeton, New Jersey

Dear Members of the Special Committee on Aging,

Community living matters to me because people who have a disability or an invisible disability need Medicaid assistance to provide them a normal life they deserve and not get judged for being different. It breaks my heart when the Republicans voted to cut Medicaid. Because in my home state of New Jersey has 30 to 50 assistance programs for people with a disability or an invisible disability. Especially kids who are suffering from these disabilities since childhood. That's the reason why community living matters most.

Michelle Carlin, Somers Point, New Jersey

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a physical therapist and treat patients with all kinds of disabilities and injuries and believe everyone deserves equal care to live the life they love.

Susana Medina, Camden, New Jersey

Dear Members of the Special Committee on Aging,

Community living matters to me because, we (husband and son with a disability are able to still live in our community. We have wonderful neighbors that he is familiar with him and care about his safety. My adult son attends a day program thank provides activities and care for my adult son that needs 24/ 7 care. That program assist with various areas of support to still be able to live in the community . And he is able to attend and worship in mass with us.
Thanks for the support,

Jacob Earwood, East Windsor, New Jersey

Dear Members of the Special Committee on Aging,

These services are essentials for families with disabilities like mine.

Having services where people come to our home is the most comfortable.

Early intervention was super important for my son. They helped us figure out a way to get an autism diagnosis which is nearly impossible in the state of NJ.

Amanda Nehme, East Brunswick, New Jersey

Dear Members of the Senate Special Committee on Aging,

My name is Amanda Nehme. I live in East Brunswick, New Jersey, and I am the mother of a four-year-old daughter, Charlee, who lives with Dravet syndrome (a catastrophic genetic epilepsy), autism spectrum disorder, and global developmental delays. She is nonverbal, has multiple seizure types, significant behavioral and safety challenges, and requires constant supervision and skilled medical support to stay safe at home and in the community.

For our family, Medicaid home and community-based services (HCBS) are the difference between Charlee growing up in her home with her parents and little brother—or being pushed toward institutional care or repeated hospitalizations.

How Medicaid HCBS impact our daily life

Charlee's seizures are frequent, unpredictable, and can become life-threatening within minutes. She has had status seizures, turning blue and requiring emergency rescue medication to stop them. Some have happened during everyday activities like a bath. Even moderately warm water, a mild illness, or excitement can trigger a dangerous event. She needs someone watching her at

all times who understands her rescue plan and can act immediately.

Medicaid HCBS touch nearly every part of our daily life:

Skilled nursing and medical oversight at home and in the community. When Charlee's in-home nursing hours are authorized, a nurse can monitor her seizures, manage her complex medication schedule, and recognize early warning signs before an emergency spirals out of control. That support keeps her out of the hospital and allows us to manage life-threatening epilepsy in our living room instead of an ICU.

Access to a pediatric medical day program in early childhood instead of institutional care. When Charlee was under three years old, she attended a pediatric medical day care program that integrated nursing, therapies, and early education. This program only accepted Medicaid. There, she received physical, occupational, and speech therapy in a setting built around children with complex medical needs, rather than a traditional childcare setting that could not safely manage her seizures or behaviors. HCBS funding is what made that community-based option possible during a critical developmental window, instead of pushing us toward long-term care or constant hospitalization. At age three, she transitioned into a preschool program, but she still needs Medicaid HCBS to make her participation safe and sustainable.

Early intervention and intensive therapies. Because of Medicaid, Charlee has had early intervention services and therapies aimed at communication, motor skills, and adaptive behavior. These are not "extras" for her—they are the tools that help her learn to participate, in whatever way she can, in family life, school, and eventually the broader community.

The ability for our family to remain economically and emotionally stable. I work full-time, and our family of four already relies heavily on my employer insurance for much of Charlee's care. But even with private insurance, her care is extraordinarily expensive and does not fully cover skilled nursing, medical programs, or the level of therapies she requires. Medicaid HCBS fills those gaps. Without it, the costs of her care would quickly overwhelm us, forcing impossible choices between her medical needs and basic expenses like housing and food.

In short, Medicaid HCBS allow Charlee to live at home, attend appropriate community-based programs, receive therapies, and be safely cared for by a combination of professionals and her family, rather than being separated from us.

What would happen if we didn't have Medicaid HCBS

We had a glimpse of that future when Charlee's Medicaid eligibility was threatened because our household income was deemed too high, despite the fact that her medical costs vastly exceed

anything a typical family can absorb. Losing or reducing Medicaid HCBS would not simply be a paperwork change for us—it would dismantle the supports that keep our daughter alive and with us.

Without Medicaid HCBS:

Charlee would be at much higher risk of preventable emergencies and death. Dravet syndrome carries a high risk of status epilepticus and Sudden Unexpected Death in Epilepsy (SUDEP). Charlee has already had prolonged seizures that required emergency medication and urgent intervention. Removing in-home and program-based nursing means more 911 calls, more ICU admissions, and a greater chance that a seizure will be the one we cannot stop in time.

She would likely lose access to the types of medically appropriate programs she needs. Programs that can safely support children with complex medical needs typically rely on Medicaid. Without HCBS, she would either be pushed into settings that cannot safely manage her seizures and behaviors, or lose access altogether, leaving us with no realistic community-based options.

One of us would be forced out of the workforce, and we still could not provide the same level of care. If Medicaid HCBS were taken away, I would almost certainly have to leave my job to try to fill the gap in supervision and care. Even then, I am not a nurse. I cannot replace skilled nursing, nor can I safely manage constant 24/7 care alone without burning out or risking mistakes. We would lose income and employer coverage at the exact moment our out-of-pocket costs skyrocketed.

The “choice” would shift from community living to institutionalization or repeated crisis care. Without HCBS, families like mine do not actually have viable options. The realistic outcomes are: a child in a nursing facility, a revolving door of ER visits and hospital stays, or a family collapsing under financial and caregiving strain. None of these paths preserve dignity, independence, or community connection—not for the person with a disability, and not for their siblings or parents.

Charlee’s developmental potential would shrink. Therapies, consistent routines, and safe exposure to the world are what allow her to make gains, however small. If the focus shifts from “How can we help her engage?” to “How do we keep her alive with fewer supports?”, her world—and ours—narrows dramatically.

Why community living matters for us

When HCBS are in place, Charlee is not just “a medically complex child.” She is a little sister who squeals when she sees her brother, a daughter who reaches for us, a student in a community-

based program, and a member of our New Jersey community. At night, she co-sleeps with us because it is not safe for her to sleep alone. We monitor her breathing and movements, knowing that a seizure can happen at any time. We eat together at our kitchen table. We celebrate small victories at home—an extra step, a new sign, a calmer transition. These are the ordinary moments that any family takes for granted, made possible for us only because Medicaid HCBS keep her safe enough to live outside an institution.

I am asking you to protect and strengthen Medicaid HCBS—not only for older adults, but for children like my daughter who will rely on these supports across their entire lives. Policies that cap or narrow access based purely on parental income, without accounting for the extraordinary cost and intensity of care, effectively punish families for trying to work while raising a medically fragile child. We need a system that recognizes that HCBS are not optional—they are foundational infrastructure that keeps disabled people in their homes, their schools, and their communities.

Thank you for considering our family's story and for holding this hearing. I hope you will look at Medicaid HCBS not as a line item, but as the reason families like mine can keep our children safe, together, and truly part of our communities.

Sincerely,
Amanda Nehme
East Brunswick, New Jersey

Jo Remster, Mannington Township, New Jersey

Dear Members of the Special Committee on Aging,

Community living matters to me because these people have enough problems without taking things away from them that makes their life a little easier.

Tonya Singleton, Ewing, New Jersey

Dear Members of the Special Committee on Aging,

Community living matters to me because, I had a stroke years ago and I have a lot of medical issues, I rely on Medicaid for my meds, because without my meds I wouldn't be able to survive, I also rely on Medicaid because they pay for my home health care and my transportation to and from my doctors appointments, without Medicaid I'd be lost. Please keep Medicaid open for people like me who can't afford healthcare and rely on Medicaid, thank you

---

Derek Binelli, Linden, New Jersey

Dear Members of the Special Committee on Aging,

Community living matters to me because it keeps people like myself healthy and happy.

Dylbere Qiku, Middlesex, New Jersey

Dear Members of the Special Committee on Aging,

Community living matters to me because they need to live a life like we do and have ample resources to assist them

---

Ed Adams, Monroe, New Jersey

Dear Members of the Special Committee on Aging,

Community living matters to me because everyone
needs a home

December 8, 2025

To the Senate Special Committee on Aging:

I would like to share the story of one of my former clients, Michael Ogg, whose life and legacy illustrate with extraordinary clarity how home and community-based services (HCBS) can determine not only the quality of life for individuals with disabilities, but whether they survive at all. Michael was a brilliant, fiercely independent man living with advanced multiple sclerosis. By the time I represented him at Legal Services, he was quadriplegic and relied on a highly customized home environment that he had carefully adapted as his physical abilities declined. HCBS supports—particularly his Medicaid-funded personal care assistance (PCA) — were the only reason he was able to remain safely in his own home.

At the time, Michael received enough PCA hours under Medicaid to cover approximately 50 percent of his daily needs. This meant that the other 50 percent of the time, he was completely alone — even though he had no functional ability to perform the most basic tasks of daily living without hands-on assistance. Despite these gaps, he remained devoted to living independently and continuing his work as a disability rights advocate. His story was later featured in *Health Affairs* ("Telling His Story To Change Policy: Remembering Michael Ogg"), reflecting how deeply he believed in the power of HCBS programs and the urgent need to expand them.

When COVID-19 struck at the very beginning of the pandemic, Michael's situation became immediately life-threatening. He contracted the virus, and it was evident that his pre-existing level of PCA support was far from sufficient for the acute needs he now faced. His managed care organization responded by dramatically increasing his private duty nursing hours — something that could not have occurred without Medicaid HCBS as the underlying framework. That increase in hours allowed him to receive the continuous care, monitoring, and medical attention he desperately needed during the most dangerous period of his illness.

I am confident that had Michael not been on Medicaid — and had HCBS supports not existed — he would not have survived long enough to even receive that emergency increase in care. HCBS quite literally allowed him to remain alive, at home, and connected to the community he loved. His story underscores a simple truth: these programs are not abstract policy mechanisms; they are lifelines. For many, including Michael, they are the difference between safety and abandonment, independence and institutionalization, and for some, life and death.

Sincerely,

Ryann M. Siclari, Esq., LL.M. (Elder Law), Certified Elder Law Attorney
Principal
Porzio Bromberg & Newman
Morristown, NJ

CONTACT
OF MERCER COUNTY, NJ

U.S. Senate Special Committee on Aging Testimony

Eleanor K. Letcher, Executive Director
CONTACT of Mercer County, NJ

December 8, 2025

Good morning, Chairman Rick Scott, Senator Kirsten Gillibrand, and distinguished members of the Committee.

My name is Eleanor Letcher, and I serve as the Executive Director of CONTACT of Mercer County, NJ. This nonprofit, community-based organization currently operates the part-time CONTACT Reassurance warmline for seniors aged 62 and older. I appreciate the opportunity to testify in support of state funding and/or legislative action to expand this aging service — both within Mercer County and across New Jersey.

CONTACT's story begins 50 years ago, when we first launched the Reassurance warmline — back then using rotary phones — to reach older adults who were living alone, frequently with no one to care for them, disenfranchised from family, suffering as shut-ins, or unable to leave their homes. These calls allowed them to engage with the outer world and to connect with real people, to share their concerns or just to chat with a caring person.

And today, those calls still save lives. One of our seniors in Trenton lived alone in a rowhouse. Because of thin walls and risky activity nearby, she would answer our daily reassurance call and say loudly, "Thank you, Officer — I have cookies for you!" to create the illusion that police were present. That sense of connection and perceived safety allowed her to remain in her home for years longer than she otherwise would have. When she finally moved, her son — a physician — expressed that without the daily calls, she likely would have entered long-term care far earlier. Over our 50 years of service, we estimate we have connected with thousands of seniors in Mercer County alone.

➢ Why This Matters — Context & Need

1. The population of older adults in New Jersey is rapidly growing.
   According to the 2025–2029 New Jersey Department of Human Services, Division of Aging Services (DoAS) State Plan on Aging, the share of New Jersey residents 65 and older rose from 13.8% in 2013 to 16.8% in 2023 — a 22% increase in a decade. As the senior population grows, the demand for not only medical but also social, emotional, and supportive services will increase sharply.

2. Programs like our telephone Reassurance programs address loneliness, social isolation, and overlooked risks. These critical programs — that offer regular check-in calls to older adults — are a proven, low-cost, scalable way to reach seniors who may be socially isolated, homebound, or cut off from regular in-person contact.

3. Especially in counties like Mercer, NJ, with significant numbers of older adults living alone or aging in place, these calls can serve as an early-warning and prevention system—simply put, they catch emerging health, mental-health, mobility, or safety issues before they escalate.

4. There is a strong alignment with State priorities and the 2025–2029 State Plan on Aging. The State Plan on Aging emphasizes the need to expand supportive services and develop comprehensive, person-centered care systems for older adults. Expanding telephone reassurance directly aligns with that goal — offering social connection, early detection of need, and support to help seniors remain safely in their homes and communities.

➢ What CONTACT's Reassurance line Does — And What Expansion Would Mean

- CONTACT's Reassurance Line provides regular check-in calls to older adults (currently part-time). Callers are trained volunteers or staff who listen for signs of distress, loneliness, emerging health issues, unmet needs (meals, medication, mobility), or signs of abuse or neglect.

- With stable funding and expanded capacity, our Reassurance program could:
  - Increase call frequency (e.g., daily or multiple times per week).
  - Enroll more older adults across Mercer County — including rural or underserved areas.
  - Serve as a model for expansion to other counties in New Jersey.
  - Partner with existing senior services, community-based organizations, and local Area Agencies on Aging (AAAs) to coordinate support, referrals, and follow-up care.

➢ Benefits of Reassurance — For Individuals, Families, and the State

- Improved well-being & mental health: Regular social contact reduces loneliness and feelings of isolation, which are otherwise associated with depression, anxiety, cognitive decline, and worse health outcomes. Telephone reassurance offers companionship and a sense of connection.

- Early detection & prevention: By catching warning signs early — whether medical (mobility, medication issues), psychosocial (isolation, depression), or safety (falls, neglect) the program can help prevent emergencies, hospitalizations, or institutionalization.

In real life, these calls make a difference: once, a senior received a phone call reporting a serious accident involving her daughter and demanding immediate money. Our counselor intervened — we reached the daughter directly, learned she was safe — and successfully prevented what would have been a devastating scam and financial loss. In another case, a scheduled reassurance call went unanswered; because of our consistent relationship with the senior, we alerted a family member, who discovered her in medical distress. She was rushed to the hospital and spent a week under care; her physicians told the family it is very likely she would not have survived if help had come later.

- Cost-effective, scalable, equitable: Compared to the cost of emergency care, long-term care, or reactive social services, telephone reassurance is relatively low-cost and can reach homebound or isolated seniors regardless of transportation, mobility, or location.

- Supports "aging in place": Helps older adults stay connected to their community, maintain independence, and live safely in their homes — reducing pressure on nursing homes and long-term care facilities.

- Aligns with state goals: Supports the vision laid out in the New Jersey State Plan on Aging for coordinated, comprehensive services for older adults.

➢ **Ask / Recommendation**

I respectfully urge this Committee to:

- Provide dedicated funding (state budget appropriation or grant) to expand CONTACT of Mercer's Reassurance Line — to evolve from part-time to full-time coverage in Mercer County.

- Include CONTACT's telephone Reassurance and social-connection services as a recognized part of the State's supportive-services portfolio for older adults under the State Plan on Aging.

- Encourage partnerships between nonprofits like CONTACT, local AAAs, community-based organizations, and local government to replicate and scale this model across other New Jersey counties.

- Monitor and evaluate outcomes (e.g., reductions in emergency hospitalizations, improved well-being, decreased loneliness) to inform future investments.

➢ **Closing**

Thank you for your time, and for considering how this simple — yet powerful — intervention can improve the lives of thousands of older New Jersey residents, support their dignity and connection, and ultimately save costs for families and the State.

When a senior, whom we only know by phone, quietly says, "I love you," it means we are often the only human connection she has. That is the real difference we ask you to support. I am happy to answer any questions or provide additional data.

Respectfully,

Eleanor K. Letcher

Eleanor Letcher
Executive Director
CONTACT of Mercer County, NJ, Inc.
60 South Main Street, Pennington, NJ 08534
609-737-2000
Eletcher.contact@gmail.com

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from New Mexico

Tonya Iseminger, Albuquerque, New Mexico

Dear Members of the Special Committee on Aging,

Medicaid's Home and Community Based Living allows my daughter—30, intellectually disabled—to have a rich social life, volunteer in her community, participate in sports, and hold a part-time job where she's been honored as an outstanding employee! All of these things enrich her life and ours, and give her the independence and confidence that all of us need as humans in the world. So many of these things would be diminished or unduly complicated or nonexistent for our family without Medicaid's HCBS program.

I. Engle, Tularosa, New Mexico

Dear Members of the Special Committee on Aging,

Community living matters to me because It does.

Chemen Ochoa, Santa Fe, New Mexico

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities need our community.

Laura Vickers, Farmington, New Mexico

Dear Members of the Special Committee on Aging,

Community living matters to me because all humans deserve a chance to thrive. When we include our special brothers and sisters, we fulfill our obligations as a civilized and caring society. If resources are taken from families with special needs citizens their lives will most likely become stressful and unmanageable thereby creating a decline in several families' mental health and well-being. Remember the people, Congress. It is us who pay your wages to serve the greater good of this country.

Jessica Castillo, New Mexico

Dear Members of the Special Committee on Aging,

Community living matters to me because it is important to feel welcomed and not a burden to anyone!

Maresa Pryor-Luzier, Datil, New Mexico

Dear Members of the Special Committee on Aging,

Community living matters to me because we need to be able to stay in our own homes and have access to good food and healthcare facilities.

Halli Bourne, Albuquerque, New Mexico

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a parent with advancing dementia and she needs care that her older children--who are all senior citizens--cannot provide because they all work full time. Currently my mother is receiving check-ins from a hospice nurse a few times a week, and, while this helps, it's not nearly enough. Congress, who is richly compensated by the American people, has failed miserably so far by taking care of us in return. So many of us are struggling just to get by. We see the hypocrisy and our tax dollars will eventually run out if Congress does not correct their current, oligarchic course.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from New York

Submission to the Congressional Record

Title: Recognition of The New Jewish Home's Adult Day Health Care Program

Introduction

The essential role of Adult Day Health Care programs, including the contributions of The New Jewish Home's Adult Day Health Care (ADHC) programs, must be recognized for supporting the health, safety, and dignity of New York City's most vulnerable older adults. ADHC programs serve a Medicaid population that is nursing home eligible but wants to age in the community.

NYC Senior Demographics and Need

New York City is home to one of the fastest-growing aging populations in the nation. Approximately 1.43 million New Yorkers are age 65 or older[1], a population that has grown by more than 50 percent since 2000[1]. Among these older adults, 36.7 percent have at least one disability[2], and nearly one in five—more than 250,000 seniors—live below the poverty line[3]. Many face additional economic stress: over 61 percent of older renters are "rent-burdened," spending 30 percent or more of their income on rent[1]. Roughly 30 percent of older adults live alone[2], increasing risks of social isolation, poor health outcomes, and preventable institutionalization[2].

Program Overview and Impact

Programs such as The New Jewish Home's ADHC provide comprehensive, person-centered clinical care, rehabilitative therapies, medication and treatment management, structured cognitive programming, and behavioral health support in a safe, community-based setting. Research demonstrates that participation in adult day health programs improves daily functioning, reduces nighttime disturbances and unsafe behaviors, eases caregiver stress, and delays or avoids nursing home placement[4]. For those who eventually require institutional care, prior participation in an ADHC program is associated with slower cognitive decline[4]. These programs deliver essential care at 50 to 80 percent of the cost of equivalent home-based services[4].

Participant Stories

The transformative impact of ADHC programs is illustrated through the lives it helps improve.

Ms. O, discharged from the hospital with complex medical needs, initially struggled with fatigue, medication management, and isolation — challenges that threatened her ability to remain at home. Through our program's coordinated clinical oversight, individualized rehabilitative therapies, and structured daily activities, she regained strength, confidence, and a renewed sense of purpose. She is now able to participate actively in community life and manage her health conditions effectively.

Ms. B, an older adult living with dementia, was withdrawn, anxious, and increasingly unsafe at home. The structured cognitive therapy, behavioral health services, and predictable daily routines offered by our ADHC program allowed her to re-establish a sense of safety and familiarity. She began to engage in social and recreational activities, experienced fewer nighttime disturbances, and regained confidence in performing basic daily tasks. Her daughter, previously overwhelmed by caregiving responsibilities, experienced reduced stress and could rely on safe, supportive care for her mother.

These cases illustrate the dual impact of ADHC programs: enhancing clients' quality of life while providing essential support for family caregivers.

Addressing Social Determinants of Health

Beyond direct care, TNJH's ADHC programs address social determinants of health that disproportionately burden low-income older New Yorkers: food insecurity, housing instability, medication and treatment adherence, and social isolation. These supports are especially crucial in underserved neighborhoods across the five boroughs, where disability, poverty, and housing burdens are most acute.

Conclusion

As New York City's aging population continues to grow, and the number of older adults with disabilities or limited income rises, the demand for community-based, medically supervised care will only intensify. Adult Day Health Care strengthens families, preserves independence, reduces avoidable hospitalizations, and ensures that older New Yorkers — regardless of income — can age with dignity.

It is imperative that access to Adult Day Health Care programs be protected and expanded, ensuring that the vulnerable older adults who rely on these services continue to receive dignified, affordable, community-based care.

Susan Holodak, MS

Administrative Manager- Adult Day Health Care Programs

(609) 879-6753

SHolodak@jewishhome.org

Endnotes

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City Harvest provides nutrition education at NORC site through SNAP-Ed funding. The July 2025 HR1 spending bill that was signed into law cuts all USDA funding for the program. Through our work at NORC sites and older adult centers, we can attest to the incredible resources that these facilities provide to seniors. Not only do they keep seniors active, but they connect them with their community and with external resources from organizations like City Harvest. Below are 2 testimonials from seniors who participate in our programming:

Testimonials

"The City Harvest Nutritional Education and Cooking Program is excellent for Older Adults. These programs provide community and insight about accessing healthy, low cost meals/dishes. Majority of Older Adults in my centers live under the poverty line and their neighborhoods do not provide too many healthy options. These programs brought awareness, education and enjoyment to our Older Adults. My older adults enjoy the educators, the connection with them was great and they are willing to try eating healthier. We look forward to having this program services our older adults." - **Joseph Dupree, Program Coordinator, Fort Greene Council**

"My name is Reginald Umpthery and I work for Fort Greene Council's Willoughby Older Adult Club. We have partnered with City Harvest for a couple of years and it has been amazing. The older adults really enjoy each session. This workshop had all of my members in the class engaged and asking questions, many of which is from their experience with nutrition. City Harvest has shown my member how to eat healthy and the benefits and consequences of each meal they eat. It eliminated the age old myth that you can't eat healthy on a budget. Many of my members speak about how this class has changed their life for the better and how they tried out the meals that were taught. I hope this partnership continues and City Harvest is doing a great deal for our community." **- Reginald Umpthery, Fort Greene Council's Willoughby Older Adult Club**

About City Harvest

City Harvest is New York City's first and largest food rescue organization. We rescue nutritious, high-quality food that would otherwise go to waste and deliver it for free to hundreds of food pantries, soup kitchens, community partners, and our own Mobile Markets® across the five boroughs. In response to the urgent and ongoing demand for food assistance and a commitment to sustainability, this year we will rescue more than 86 million pounds of food and deliver it to New Yorkers experiencing food insecurity. With deep connections to the communities where we work and with a focus on localized investment, City Harvest is dedicated to strengthening our network of agency partners and the local food system through capacity building, advocacy, and nutrition education. Through our food rescue model, we support environmental health—this year, we will prevent the equivalent of more than 25.4 million kilograms of CO2 from entering the atmosphere—while providing New Yorkers with the food they need to thrive. City Harvest is recognized as a leading equity-driven organization and has been named one of America's Top

100 Charities by Forbes. Since our founding in 1982, we have rescued more than one billion pounds of food and provided it for free to our neighbors in need.

Statement for US Senate Special Committee on Aging

12/03/2025

My name is Sue Ruff. I am a person who has disabilities. I am also the parent of a person with multiple disabilities. I grew up with a brother who was born with developmental and heart conditions. As my parents aged, they, too, had to deal with health issues that affected their lives. Disability touches everyone at some point.

I have worked at an Independent Living Center for more than thirty years. I work forty hours a week. My first job at the ILC was in supported employment. I helped people (that many thought could not work), find and keep jobs. I then transferred to a program at our center that worked with children birth to five and their families. And after a few years I was asked to work on disability rights, which is still my current job.

Home and Community Based Services (HCBS) keep people with disabilities in their own homes and communities, in integrated and inclusive settings. My brother was born in 1959, before the passage of 94-142 (IDEA). Doctors told my parents to place him in a nearby institution and tell the rest of the family he had died. They told the doctors NO. The pediatrician the rest of us children saw was generally unwilling to take care of my brother. There were few options for his education and my parents had to fight very hard to get him into a program run by a not-for-profit. He wanted to go to school with his brothers and sisters, but that was not allowed. And my father's employer would not pay for any health insurance for my brother, so his doctor's visits and medicines were paid for by my folks.

My dad was a farmer and a factory worker. My mother was a teacher who left the field to take care of her six children, mostly to care for my disabled brother. My father gave five years of his life in the Pacific theatre in WW II. He was a naturalist who could identify trees, plants, bird songs, animal tracks. He was also an athlete who could have played professional baseball but had to help on his family's farm when he was a teen. My mother never really stopped teaching and often helped the children of friends in our small town, when those children struggled with schoolwork.

Our next-door neighbor was a hospital CEO and he would not let the hospital and doctors bill my parents when my brother was hospitalized at age 12. My brother died of congestive heart failure in 1972. My brother was dearly loved and cared for by our family during a time when so many children were placed in state institutions. He was a great teacher, too. He taught love.

My daughter has six disabilities. She lives in her own apartment and has staff support for about 50-60 hours a week. The other hours of support that she needs are provided mostly by me, but also by other family members. HCBS enables her to be independent

and to participate actively in her community here in the Southern Tier of NY. She attended a local school (was a Girl Scout, choir member, and cheerleader while working on her education in inclusive classes). She was employed for a few years, but a brain injury in her early twenties severely limited her employment prospects. She volunteers, sings in a local choir, goes to the Y, plays with her nieces, and spreads a lot of love around. She is aging. So am I.

Over the decades I have known very many people who were placed in institutional settings. Every one experienced abuse or neglect or both. For those that were helped by the Independent Living Center or by HCBS, life changed dramatically. Trauma from abuse or neglect never goes away. But HCBS opens the doors to real life opportunities.

When people with disabilities live independently with supports and services, they have the chance to contribute to the fabric of our society, to be valued and to share their individual gifts. We are not asking for charity. We are YOUR family and YOUR neighbors and OUR LIVES are important. We are YOUR COMMUNITY.

Job Path, based in New York City and founded in 1978, supports hundreds of adults with autism and other developmental disabilities every year in the workplace, the community, and at home. With Job Path support, people can explore what they want out of life and chart their own journey.



For three decades, we've been honored to provide Home and Community-based services through our Supported Living program to one of the pioneers in the disability rights movement. Nina G. was one of the named plaintiffs in the historic Willowbrook Consent Judgement, signed in 1975, which led to the shuttering of the infamous institution, which was rife with abuse and neglect.



Willowbrook was finally closed after years of advocacy from people including Nina's mother, Diana McCourt, and an expose from Geraldo Rivera. Nina does not communicate verbally, has a profound intellectual disability, and - in her youth - had significant self-harming behavioral challenges. After several other residential settings, Nina came to Job Path more than 20 years ago, and has lived in community-based environments since then.



Now 64, Nina has her own room festooned with one of her favorite things - butterflies - in a spacious 3-bedroom apartment with two other Job Path participants and round-the-clock support from Job Path staff. Over the years, Nina has joined in at holiday parties and celebrations, taken classes in arts and music, enjoyed the outdoors, and travelling throughout the city, as well as the regular, everyday life of *community* - meals, laughter, games, friendship.



As one staff member puts it: "Nina knows much more than she lets on." These days she enjoys lounging in her recliner, listening to music, indulging in sweets, and she lights up when her favorite support worker comes into the room. Over the years, as Nina's interests and needs have changed, Job Path has been able to respond.

After a recent screening of a Willowbrook documentary Nina's mother recounted what it was like for her daughter to move to community-based care two decades ago.

"She looked in the door and was a little suspicious but she did a little hop and skip. That day almost all her behaviors changed and she didn't hurt herself any more ... I learned that the environment you have people in is going to nurture them, or kill them and Job Path is a nurturing place."

Job Path - 256 W. 38th Street, New York, NY 10018
jobpathnyc.org



1 Van Tromp Street, Albany, NY 12207
Phone: (607) 329-0507
Website: www.alliance-nys.org
Email: tallen@alliance-nys.org

December 2, 2025

The Hon. Rick Scott
Chairman
Senate Special Committee on Aging
110 Hart Senate Office Building
Washington, DC 20510

The Hon. Kirsten E. Gillibrand
Ranking Member
Senate Special Committee on Aging
110 Hart Senate Office Building
Washington, DC 20510

RE: Statement for the Record – Senate Special Committee on Aging Hearing: "Aging in Place: The Impact of Community during the Holidays"

Dear Chairman Scott and Ranking Member Gillibrand:

On behalf of The Alliance of Traumatic Brain Injury (TBI) and Nursing Home Transition and Diversion (NHTD) Waiver Providers of New York ("The Alliance"), thank you for the opportunity to submit this statement for the record for the Senate Special Committee on Aging's hearing on the importance of community living for older adults and people with disabilities.

The Alliance represents providers delivering specialized home and community-based services (HCBS) under New York's Medicaid TBI and NHTD 1915(c) Medicaid waiver programs, which help individuals who require nursing home-level care live independently at home. Serving over 13,000 New Yorkers and employing thousands of professionals and home health aides, these programs save federal and state dollars while improving health outcomes, independence, and quality of life.

As the Committee continues its work to strengthen community living for older adults and people with disabilities, we urge you to consider the challenges facing Americans across all states like the vulnerable populations of New Yorkers who rely on the TBI and NHTD waiver programs. These waivers are lifelines for individuals with traumatic brain injuries and cognitive or physical disabilities, allowing them to

remain in their homes rather than in costly institutional settings. Yet, these programs face mounting threats that could undermine access to care.

These challenges include:

Access Issues from Federal Medicaid Financing Reform. Medicaid reforms included in Public Law No. 119-21 will have real consequences for the people we serve. These changes will tighten state Medicaid budgets, and programs like the 1915(c) waivers, which make community living possible, are often the first to feel the impact. When funding shrinks, providers are left with impossible choices: reduce services or close their doors. Added administrative hurdles, like frequent eligibility checks and retroactive coverage rules, create gaps in care that leave vulnerable individuals waiting for help they desperately need. Protecting these waivers is essential to preserving community living options for thousands of vulnerable individuals.

Capacity Issues from Conflict of Interest Implementation. The federal Conflict of Interest (COI) rule adds another layer of complexity. While designed to protect individuals, it has created serious barriers to continuity of care. Under CMS's HCBS Final Rule, providers delivering services under 1915(c) waivers cannot both deliver services and develop person-centered plans. In practice, across New York State this has led to provider shortages and delays, especially for waiver populations like TBI and NHTD. Conflicting definitions of COI across federal statutes only make the problem worse, causing unnecessary hospital stays and even nursing home placements. The human impact is real: one participant with complex medical needs waited months for basic supports like meal preparation and appointment coordination, and in another heartbreaking case, an individual died while waiting for placement on the TBI waiver. These stories show why federal leadership is urgently needed to align COI rules and provide a regulatory/legislative fix to protect access to care.

Lastly, the Alliance is increasingly concerned about the proposed enrollment cap on the NHTD waiver, which would limit participation to 9,400 individuals for three years once approved by CMS. While intended to manage costs, this cap would limit access to services. For providers, it means turning away individuals who could safely remain in their homes, forcing them into nursing facilities at greater expense to Medicaid and with far less independence.

The Alliance would be glad to serve as a resource for you and your staff in your work on the Senate Special Committee on Aging. We would welcome the chance to meet in the coming weeks to discuss our initiatives and how we can support your priorities.

Thank you for your attention to these issues and for your commitment to helping older adults and people with disabilities live with dignity in their communities.

Best,

John McCooey
Chairman
The Alliance

Traci Allen
Executive Director
The Alliance

The Arc Oneida-Lewis Chapter A chapter of The Arc New York

"I'm Robert Hirt, and I'm proof that HCBS works!"

Pre and Post-Secondary Education Success



In middle school, he was introduced to School-to-Work, a group of programs provided by The Arc, Oneida-Lewis Chapter. "They taught me how to cook and how to count change. I visited, and I explored a lot of different jobs in the community," said Robert. From there it was on to CollegeWorks - a post-secondary college experience of The Arc, housed at Mohawk Valley Community College in Utica. "That's where things really took off for me. I was excited when I got accepted because I could keep busy and hang out with a lot of new friends. I did an internship, and I learned a lot on the job site." Robert was able to blend in with the rest of the College community, taking advantage of all the amenities and campus activities afforded to all students. "Visiting the library and going swimming. And if you get close to people, you make a bond that's never breaking," added Hirt.



Ready, Willing, and Able to Join the Workforce

After his graduation in 2017, Robert searched for competitive employment in the community. Success wasn't instantaneous. He applied and searched for a job for the better part of two years. In 2019, with assistance from The Arc's Supported Employment program, Robert learned of an opening at Progress Industries, an integrated business enterprise of The Arc.

"I'm happy they accepted me here. I make minimum wage, and I look forward to getting my paycheck. You don't earn money sitting around. This is a hard-working job." For Robert, it's more than work; it's a purpose and a way to be a contributing member to his community. "The people at my job are really friendly and understanding. They're like my family."

Eager to Take Center Stage

Because Robert has met so many people, it has led to other opportunities and experiences he says he wouldn't have known about. One of those is StageWorks, another program at The Arc. Designed to provide awareness, inclusion, and opportunities for people with disabilities with interests and talents in the creative and performing arts. "I found out from someone I met at CollegeWorks. When she told me about StageWorks, I said, 'Why not get up on stage and try some acting?





You get to dress up in costumes, you get to sing a lot, and [the people in the audience] always have a smile on their faces." Robert also regularly accesses the Night Rec program through Community and Family Services, where people go out into the community to eat, go to the movies, attend sporting events, shop, or engage in other leisure activities. "These programs are a lifeline for me and my friends," says Robert.

Proof Positive That HCBS Works

When asked how his life would be different today without them, he offers this: "If there were no more programs, then it wouldn't keep people occupied. I would be bored. These programs get kids away from the video games and out in the community to meet new people."



Today, Robert is a shining success and example of what supports, services, and opportunities have done for him over time. He continues to work and thrive at Progress Industries, and was even asked to speak at the 2023 CollegeWorks graduation ceremony as a graduate success. "They need more programs, people love these programs, and if there were more, then everyone would have something to achieve. They have been life changing for me."

The Harry and Jeanette
Weinberg Center for Elder Justice
AT THE HEBREW HOME AT RIVERDALE

Testimony for the Senate Special Committee on Aging Hearing

December 8, 2025

Thank you for the opportunity to submit this statement. I'm writing on behalf of The Harry and Jeanette Weinberg Center for Elder Justice at the Hebrew Home at Riverdale. We are the nation's first elder abuse shelter and a specialized safe haven for older adults experiencing harm. For more than twenty years, our mission has been to step in where systems fall short, filling the gaps that too often leave older adults with nowhere to turn when safety, stability, and independence are at risk.

As the Senate Committee examines the importance of community living and Home and Community-Based Services (HCBS), it is critical to recognize that elder abuse is one of the most profound threats to an older adult's ability to age in place. Abuse in later life is not rare, and it is not benign. Globally, it is estimated that 1 in 6 older adults experience some form of elder abuse each year[1]. It strips older adults of the very tools they need to remain in their communities: financial security, housing, social supports, medical care, autonomy, and the confidence that the people around them can be trusted. Financial exploitation alone accounts for an estimated $28.3 billion stolen from older adults in the United States each year, draining the very resources required for safe, stable community living.[2] For many of the individuals we work with, abuse is what pushes them out of their homes. It is not age or illness, but the absence of a safety net that understands their unique needs.

Elder abuse often occurs within relationships of dependency: intimate partners, adult children, grandchildren, caregivers, or others who control access to food, medications, transportation, or income. When the person who helps you get dressed or manages your Social Security check is also the person causing harm, the path to safety becomes extraordinarily complicated. This dynamic is what contributes to the invisibility of older survivors and is one reason abuse is so tragically underreported.

When older adults lose the ability to age in place due to abuse, the consequences are immediate and destabilizing. Survivors may be forced into institutional settings because there is no safe alternative in the community. Others may have no choice but to allow someone to move into their home under the guise of providing support, only to experience further exploitation. For individuals who have already lost financial resources, housing, or access to benefits because of abuse, even the most robust HCBS programs cannot bridge the gap alone. Community living is not sustainable without community safety.

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[1] "Abuse of Older People," *World Health Organization*, accessed November 24, 2025, https://www.who.int/news-room/fact-sheets/detail/abuse-of-older-people.
[2] "AARP Report Finds $28.3 Billion a Year is Stolen from U.S. Adults Over 60," *AARP*, accessed December 8, 2025, https://press.aarp.org/2023-06-15-AARP-Report-Finds-28-Billion-a-Year-is-Stolen-from-US-Adults-Over-60.

That is why elder justice must be understood as a core component of HCBS, not an auxiliary service. If the goal of HCBS is to preserve independence, dignity, and autonomy, then we must address the forces that erode these conditions. Elder justice interventions are health interventions, housing interventions, and community-stability interventions. They are integral to any system that aims to keep older adults safely connected to their communities.

At the Weinberg Center, our work is built around a coordinated, multidisciplinary response. The team is made up of attorneys, social workers, medical professionals, public health specialists, and community partners working together on every case to restore stability and rebuild safety. Our model is designed not only to interrupt harm, but to return older adults to the community whenever possible, with supports that reflect the full complexity of their lives. This includes our national network, the SPRiNG Alliance, which connects elder justice shelters across the country and strengthens the replication of this model so that no older adult is left without options.

We also know this model works. According to NYAM's 2024 evaluation of elder justice shelters, including the Weinberg Center, participants reported increased security, greater stability, and improvements in mental, physical, and financial well-being.[3] The evaluation demonstrates that this multidisciplinary model is effective because it stabilizes every domain of a survivor's life, including health, housing, finances, safety, and social support, rather than addressing any single issue in isolation. These are the precise conditions that make it possible for older adults to return safely to the community. Senator Gillibrand's recent report, *Age of Fraud: Scams Facing Our Nation's Seniors*, documents the escalating scale and sophistication of financial exploitation targeting older adults[4]. This report highlights the urgent need for coordinated elder justice interventions that prevent unnecessary institutionalization and strengthen community living. Her findings mirror what our experience has shown for years: when specialized elder abuse programs are available, older survivors can remain safely in their homes and communities.

But the need far exceeds the resources currently available. Across the country, elder abuse shelters and multidisciplinary elder justice programs remain limited, unevenly distributed, and often unsupported by federal funding streams. To meet the scale of the problem, we need dedicated federal investment in elder justice capacity-building, technical assistance, and shelter development, particularly within HCBS frameworks. Without this investment, older adults will continue to fall through the cracks, and the

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[3] "Need, Access, Impact, and Opportunities: Findings from a Multi-Site Evaluation of Elder Justice Shelters in the U.S." *NYAM*, accessed on December 8, 2025, https://theweinbergcenter.org/wp-content/uploads/2024/04/NYAM_CEAR_EJS_Evaluation_Report_Mar24_FINAL.pdf

[4] "Age of Fraud: Scams Facing Our Nation's Seniors." *U.S. Senate Special Committee on Aging*, accessed on December 3, 2025, https://www.aging.senate.gov/imo/media/doc/age_of_fraud_scams_facing_our_nations_seniors.pdf

The Harry and Jeanette
Weinberg Center for Elder Justice
AT THE HEBREW HOME AT RIVERDALE

promise of community living will remain out of reach for many of the people who need it most.

We also want to emphasize how important it is for the Senate to continue hearing from elder justice providers and survivors. Older adults experiencing abuse are among the least visible constituents in policy conversations, not because the need is small, but because the barriers to speaking out are so profound. Continued federal attention helps ensure that their experiences are not overlooked and that elder justice remains a priority in national aging policy.

Thank you again for the opportunity to share this perspective. Older adults deserve to live safely, independently, and with dignity in their communities. To realize that vision, elder justice must be recognized as essential to HCBS and the systems designed to support aging in America must fully reflect the needs of those most vulnerable to harm. We look forward to supporting the Committee's work in any way we can.

United States Senate Special Committee on Aging

Honor Rick Scott, Chair & Honorable Kirsten Gillibrand, Ranking Member

Submitted by: Kayleh Levy-Weller

December 8, 2025

Thank you, Chair Scott and Ranking Member Gillibrand, and members of the Senate Special Committee on Aging for holding this hearing and for the opportunity to submit testimony. My name is Kayleh Levy-Weller, and I am the Lead for Strategic Planning and Grants in the Caring Department at UJA-Federation of New York.

Established more than 100 years ago, UJA-Federation of New York is one of the nation's largest local philanthropies. Central to UJA's mission is to care for those in need—identifying and meeting the needs of New Yorkers of all backgrounds and Jews everywhere. UJA supports an expansive network of nearly 100 nonprofit organizations serving those that are most vulnerable and in need of programs and services and allocates roughly $200 million each year to support older adults, combat poverty and food insecurity, nurture mental health and well-being, strengthen Jewish life, and respond to crises here and across the globe.

UJA-Federation of New York supports a range of community-based initiatives that help older adults and people with disabilities remain socially connected, engaged, and able to live independently. Five programs in particular—**Verve 55+ Living**, **Social RX**, **UJA on the Way**, our **Benefits Navigation Initiative,** and the **N/NORC Program**—demonstrate how targeted social supports, proactive outreach, and practical assistance contribute to stronger community living and prevent unnecessary institutionalization.

Verve 55+ Living: Reducing Isolation Through Connection and Purposeful Engagement
Verve 55+ Living operates at four community centers in the New York suburbs—two in Westchester and two on Long Island—to foster meaningful engagement among adults aged 55 and older. Each location employs a dedicated professional who develops high-quality cultural, educational, wellness, and social programming designed for this life stage. Activities such as arts workshops, food-based programs, group hikes, and weekly meetups help participants build friendships, strengthen social networks, and reduce loneliness.

One widower on Long Island shared that after losing his wife—his primary source of daily companionship—he struggled with profound isolation. Through Verve 55+, he joined a men's group where he found both support and friendship. He later became a regular participant in a weekly "What to Do in Retirement" circle, where older adults discuss the joys and challenges of navigating a new chapter of life. These programs provided him with a renewed sense of purpose and connection at a vulnerable moment.

Social RX: Identifying Isolation and Navigating Complex Systems
Through the Social RX initiative, community centers employ Connection Specialists who proactively identify isolated older adults and serve as trusted guides through health, social service, and community systems. Specialists maintain relationships with hospitals, government agencies, mental health providers, transportation programs, and local nonprofits, ensuring that individuals can be connected to the right supports at the right time.

A striking example comes from a group of four older adults on Long Island who were experiencing extreme loneliness—so much so that they regularly checked into their local emergency rooms on weekends simply to be around people. Hospital staff, who affectionately but worriedly referred to them as "frequent flyers," ultimately referred them to Social RX. Through consistent outreach, social connection, and coordinated support, these individuals are now building relationships and engaging in programming that reduces their isolation. Their improved well-being has also reduced unnecessary ER utilization and eased pressure on hospital systems already facing staffing shortages.

Connection Specialists help address exactly these kinds of challenges—loneliness, transportation barriers, difficulty securing home care, confusion around benefits, and caregiver strain—which, if unaddressed, lead to avoidable crises and increased institutional care.

UJA on the Way: Overcoming Transportation Barriers to Community Participation
Transportation is one of the most significant obstacles to community living in suburban regions, especially for older adults and people with disabilities. Launched in 2025, UJA on the Way is a coordinated ride-access initiative developed in partnership with community centers across Long Island and Westchester.

The program provides reliable transportation to local programs, volunteer opportunities, social gatherings, and community activities through partnerships with taxi companies, rideshare platforms, and agency-operated accessible vans. Staff at each center assist participants with booking rides, coordinating schedules, and maintaining regular outreach.

For a group of young women with autism living in Westchester, transportation had long been the primary barrier preventing them from joining community programs. Through UJA on the Way,

they now travel independently to weekly activities where they build social skills and friendships. A single transportation solution dramatically expanded their opportunities for community participation.

Benefits Navigation: A Critical Foundation for Independent Living
Maintaining independence often requires sustained access to Medicaid, SNAP, early intervention services, employment supports, and other benefits—yet the systems governing these supports are often confusing and burdensome. Many older adults and people with disabilities lose vital services not because they are ineligible, but because forms are difficult to complete, communication is inaccessible, or recertification requirements are unclear.

UJA-Federation's Differing Abilities Committee identified a deep need for benefits navigation and systems guidance across the disability and caregiver community. In response, UJA-Federation is investing in benefits-navigation professionals at three community centers who assist individuals and families in accessing government benefits, understanding school-based supports, identifying employment pathways, and securing respite and caregiver resources. One family in an Orthodox Jewish community—fearful of stigma and unsure how to advocate for their son—struggled for years to understand the special education supports available to him. Through the benefits-navigation program, they received technical case management and peer support to navigate the IEP process, helping them secure the services their son needed to thrive.

N/NORC Program
Naturally Occurring Retirement Communities (NORCs) and Neighborhood Naturally Occurring Retirement Communities (NNORCs) – collectively referred to as N/NORCs – are multi-age housing developments or neighborhoods, respectively, that were not originally developed for older adults but are now home to a significant number (at least 40%) of older people. N/NORCs were founded more than 40 years ago with the goal of transforming residential complexes and neighborhoods to meet the needs of a growing cohort of older residents and enable them to remain living independently in their homes, thrive in their communities, and delay hospitalization or nursing home placement.

N/NORC programs provide case management services, nursing services, recreational, social and cultural activities, volunteer opportunities, and ancillary services tailored to meet the needs of each community. By providing culturally and linguistically diverse staff to administer wellness checks and organize community activities, N/NORCs provide both support to individuals struggling with social isolation while simultaneously working to actively combat this phenomenon with intentional opportunities to connect. This makes N/NORCs an integral part of the combatting social isolation landscape.

One powerful example comes from a 94-year-old resident of the Penn South NORC in Chelsea—the first NORC in the United States. For years, she found joy in the community's classes, discussions, and social gatherings, but as her memory declined, she began withdrawing from activities she once loved. Traditional programming no longer felt accessible to her, and she and her loved ones worried she would lose the connections that anchored her to her community.

Through the NORC's dementia-friendly programming—designed specifically to support individuals with cognitive changes—staff were able to help her remain engaged. With tailored activities, trained facilitators, and an environment that prioritizes dignity and inclusion, she now participates fully in programs that are structured for her needs. This support has allowed her to maintain social ties, preserve a sense of belonging, and continue living safely and meaningfully in the community she has called home for decades.

Conclusion

Verve 55+ Living, Social RX, UJA on the Way, UJA-Federation's benefits-navigation initiative, and the N/NORC Program all reinforce the same principle: community living requires dependable social connection, reliable mobility, and clear pathways to essential supports. These programs help older adults and people with disabilities maintain independence, prevent isolation, and participate fully in community life.

We urge Congress to invest in social connection initiatives, transportation access, HCBS infrastructure, and benefits navigation so that individuals across the age and disability spectrum can continue to live safely and meaningfully in their communities.

Testimony of Stanfort Perry,
CEO, AHRC Nassau and Citizens Options Unlimited

United States Senate Special Committee on Aging Hearing:
Home- and Community-Based Services

December 8, 2025

Chairman Scott, Ranking Member Gillibrand, and Members of the Committee,

Thank you for the opportunity to share written testimony about home- and community-based services (HCBS) and their support of older adults with intellectual and developmental disabilities (IDD) to participate in the community.

My name is Stanfort Perry, and I serve as Chief Executive Officer of disability services agencies, AHRC Nassau, a chapter of The Arc New York, and Citizens Options Unlimited. I have dedicated my career to providing people with intellectual and developmental disabilities a lifetime of quality supports and now oversee the operation of the largest residential services network in New York State.

I. Changing Population, Challenging Funding Landscape

There's a service flashpoint coming. The community-living models created about forty years ago[1] for people with IDD to thrive and flourish are challenged in responding to the increasingly complex needs of a population that is growing older.

The number of people served by Long-Term Services and Supports from state IDD agencies increased by 80% from 2000 to 2020.[2] At the same time, people's needs are being

[1] Larson, S.A. et al. "30 Years of Community Living for Individuals with Intellectual and/or Developmental Disabilities (1987-2017)." Administration for Community Living, U.S. Department of Health and Human Services, 2021. Retrieved from: https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/30%20Years%207-13-21.pdf. Accessed 8 Dec. 2025.

[2] Residential Information Systems Project. "How Did the Number of People Getting LTSS Change Between 1988 and 2018?" University of Minnesota, Research and Training Center on Community Living, Institute on Community Integration, n.d. Retrieved from: https://publications.ici.umn.edu/risp/infographics/how-did-the-number-of-people-getting-ltss-change-between-1988-and-2018. Accessed 4 Dec. 2025.

identified more precisely through refined medical understanding, such as increased autism diagnoses[3] and dual-diagnoses of IDD with co-occurring mental health conditions.[4]

As a consequence of these advancements, service providers can identify higher behavioral and clinical needs. Yet, they are struggling in real time to retool programs — to bridge the gaps of what these models were originally designed to do, what people actually need, and what Medicaid funding supports.

A primary HCBS example of this service bottleneck is New York State's ongoing waiting list for Certified Residential Opportunities (CRO) or placements in Medicaid-funded residences.[5] Priority status is given for the emergency placement of people with co-occurring mental health and behavioral needs. Higher levels of care require additional resources outside current reimbursement structures (e.g., more frequent emergency room visits, psychiatric services, and increased staffing ratios).

The changing population makes it difficult for agencies to keep pace with the need. Moving forward successfully will require data-informed decisions and more proactive service models to reflect the current needs of this population.

II. Aging in Place, Difficult Under Current HCBS System

As people with IDD age, they face the same chronic conditions as the typical population.[6] However, the IDD population experiences additional complications: "unrecognized or poorly managed health conditions (e.g., visual and hearing impairments, mental health problems) and higher rates of morbidity and mortality than the general population."[7]

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[3] Hibbert, C.M. "What Is Causing Autism Rates to Rise? And Should We Be Concerned?" *Northeastern Global News*, 13 March 2025. Retrieved from https://news.northeastern.edu/2025/03/13/autism-rates-rising-cause. Accessed 8 Dec. 2025.

[4] Lineberry, S. et al. "Co-Occurring Mental Illness and Behavioral Support Needs in Adults with Intellectual and Developmental Disabilities." *Community Mental Health Journal*, Vol. 59,6, 2023. Retrieved from: https://pmc.ncbi.nlm.nih.gov/articles/PMC9899157. Accessed 4 Dec. 2025.

[5] Neifeld, K. "Letter to the Honorable Liz Krueger and the Honorable Helene Weinstein." New York State Assembly, 24 Mar. 2023. Retrieved from: https://nyassembly.gov/write/upload/publichearing/001347/004789.pdf. Accessed 8 Dec. 2025.

[6] Pimlott, N. "Aging With Intellectual and Developmental Disabilities: Family Physicians Can Make a Difference." *Canadian Family Physician*, Vol. 65, Supp.1, 2019. Retrieved from: https://pmc.ncbi.nlm.nih.gov/articles/PMC6501715/#:~:text=Persons%20aging%20with%20IDD%20experience,mortality%20than%20the%20general%20population. Accessed 4 Dec. 2025.

[7] Ibid.

The current HCBS funding model doesn't account for age-related needs. The same funding structure is applied regardless of age-related challenges or increasing medical complexity.

Roz Adler is 83 and supported by Citizens Options Unlimited in an Intermediate Care Facility (ICF). Roz lived independently for many years in a supported apartment. She was a fierce advocate, encouraging peers to speak up, traveling to Albany to rally, and serving on the AHRC Nassau Board of Directors sharing her lived experience as an adult with IDD.

Roz had a medical crisis in 2013 requiring extensive surgery, a feeding tube, and rehabilitation.

Due to Roz's increased medical needs and a lack of relevant HCBS funding, she was not able to return to living independently. She had to leave her friends and neighbors and eventually transition to an ICF because appropriate supports were not available to her through current reimbursement models.

Continuity of care within a service network helped Roz maintain her health, after she had difficulty speaking, bathing independently, and began using a custom tilt wheelchair. Roz, like many people with IDD, relied on long-time staff and her guardians to advocate for her needs.

Roz says she feels young at heart most days, yet current community-living models were not initially set up with the expectation that people like Roz would lead long lives. Many HCBS residences on Long Island were purchased about 40 years ago without this expectation. Consequently, Individualized Residential Alternatives (IRAs), such as group homes or apartments, may lack barrier-free accessibility — multiple levels without ramps, narrow doorways, inaccessible bathrooms, and need for modifications like walk-in showers or handrails in the bathroom.

The focus on deinstitutionalization and progression into community living was then bold and innovative. Now, however, the costs of keeping people aging safely in place can be cost-prohibitive for agencies and limit access to full participation in the community.

While agencies are funded for continuum of care, IRAs are not set up for higher levels of need. One-to-one staffing or nursing are possible supports, but not reimbursable.

III. Age and Life Stage Not Accounted in HCBS Reimbursements

Smaller providers and programs are closing because of inadequate reimbursements, rising

operational costs, the effect of inflation, and an escalating staffing crisis[8] across the country. Effective billing by agencies has never been more important. Yet, agencies struggle within these constraints to balance funding needs with the interests and preferences of older people.

David Markowitz, a resident of an AHRC Nassau group home, will turn 98 in February. He would like to retire. He can't because of larger funding and staffing issues. For David to stay at home he would need to be enrolled in Community Habilitation where a Direct Support Professional (DSP) would provide individualized day services to him in his home or in the community. The issue becomes that due to limited staffing and high turnover, should a community habilitation worker not be present for the shift due to personal reasons or perhaps a vacancy in the position, the care would default to the provider. This, then, is not a reimbursable service, but falls to the provider to provide the care.

His daily schedule must fit into HCBS program buckets, like going to day program where he is encouraged to take part in an activity or socialize. He wants to be active but doesn't have the same interests as when he was younger and needs the flexibility to design a day that meets his needs with appropriate staffing that is reimbursed.

David remembers President Franklin Roosevelt speaking on the radio. He was part of the first wave of people leaving their families to live in group homes and working on the assembly line at a sheltered workshop.

Today, David experiences mobility issues and chronic discomfort that comes from age, like arthritis, stomach issues, and headaches. He is still active and healthy – but most enjoys reading the morning paper and visiting his local diner.

David's continued health and independence rely on HCBS for consistent staffing and institutional knowledge. Even supported by people who understand how he communicates and his preferences, there are limits. Our current reimbursement structure prevents the creation of a reimbursable person-centered plan that fully meet David's needs.

IV. Growing Older at Home, Without Services

There are a number of parents of advanced age who are just starting to consider community-living settings for their aging children. Research shows parents caring for adult children with IDD into their older years have "poorer health and well-being;" those, living

[8] Rice T. & Dawson L. "The State of America's Direct Support Workforce Crisis 2025." ANCOR, 2025. Retrieved from https://www.ancor.org/resources/the-state-of-americas-direct-support-workforce-crisis-2025. Accessed 4 Dec. 2025.

with their children, “are a particularly vulnerable group. At age 71, these parents had poorer psychological well-being, more physical health symptoms, greater obesity, and fewer visits with friends or relatives.”[9]

This conversation will soon be impacting agencies around the country as “around 75% of adults with a disability live with an aging parent or other caregiver, and most are not connected to public supports or services. As a result, aging parents and family members frequently serve as unpaid primary caregivers for their family member with I/DD.”[10]

The importance of planning what happens after primary family members pass can be challenging and leads to increased reliance on continuity of care in later years.

As people with disabilities age out of their family homes, different types of residential supports will be needed and new billing systems. The difference between HCBS and ICF funding models can be stark — whereas HCBS is waiver-based funding for smaller community settings (IRAs) with services provided in the community, ICFs have “all-in-one” bundled rate system, with built-in services, such as 24/7 staffing and nursing supports, physical therapy, medical care, and nutrition services.

A more nuanced funding approach is urgently needed that takes into consideration diverse medical needs and supports that arise from aging. Sometimes, it is not as straightforward as David or Roz’s experiences but requires more flexible funding structures to adapt services and provide true accommodations as people grow older.

V. Education and Awareness for Families, Medical Providers

For families, it can come as a shock when people with IDD experience age-related health challenges earlier in life from “biological factors related to syndromes and associated developmental disabilities, limited access to adequate health care, and lifestyle and

[9] Namkung, E.H. et al. “Lifelong Parenting of Adults With Developmental Disabilities: Growth Trends Over 20 Years in Midlife and Later Life.” *American Journal on Intellectual and Developmental Disabilities*, Vol. 123,3, 2018. Retrieved from: https://pmc.ncbi.nlm.nih.gov/articles/PMC6442468. Accessed 4 Dec. 2025.

[10] The Arc of the United States. “There’s No Place Like Home: The Arc Releases A National Study on Disability Housing.” *The Arc Blog*, 24 Jan. 2020. Retrieved from: https://thearc.org/blog/theres-no-place-like-home-the-arc-releases-a-national-study-on-disability-housing. Accessed 5 Dec. 2025.

environmental issues."[11] Increased education among medical professionals and family supports would be a valuable offering through home- and community-based services.

Marianne Barbera, a retired teacher, lost her sister, Susan Auletta, in 2021. Susan was 53 when she passed away due to age-related decline typical for people with Down Syndrome. Over the course of five and a half years, Susan — who had loved telling jokes, was proficient in sign-language, dancing, and being the life of the party — lost her speech, mobility, experienced debilitating seizures, and became completely reliant on others.

Initially, staff and behaviorists noticed subtle shifts and suspected the beginning of dementia. These changes were minor the first year. Susan visited a neurologist, who essentially said "she had a nice life." In the same way, Marianne's parents advocated for Susan's schooling, Marianne knew this wasn't good enough for Susan. Marianne began keeping a detailed diary of Susan's behaviors and health — reviewing it revealed no clear warning sign. Later, a neurologist more knowledgeable about IDD and Susan's likely health journey, offered more useful medical advice.

Marianne likens the onset of Susan's dementia to holding hands with her sister and seeing a tractor trailer headed their way. In tribute to her sister, Marianne is an active advocate bringing attention to the issue of aging with disability and volunteering weekly at AHRC Nassau. Marianne teaches music and movement knowing how her sister thrived when engaged — and how activities that are tailored to people's interests unlock memories and build connections.

VI. Conclusion

The long-term viability of home- and community-based services has become a growing concern. It's time to build on the lessons learned over the decades of community living and use all of our data, lived experience, and technology to advance a bold, new plan for the future.

What is needed is not only a funding structure that is flexible to meet the needs of a changing and aging population, but a real investment in service providers.

Rather than relying on shifting state investments, the federal government should dedicate a steady funding stream focused on the needs of people with IDD. An area to start would be to move forward the "Recognizing the Role of Direct Support Professionals (DSPs) Act"

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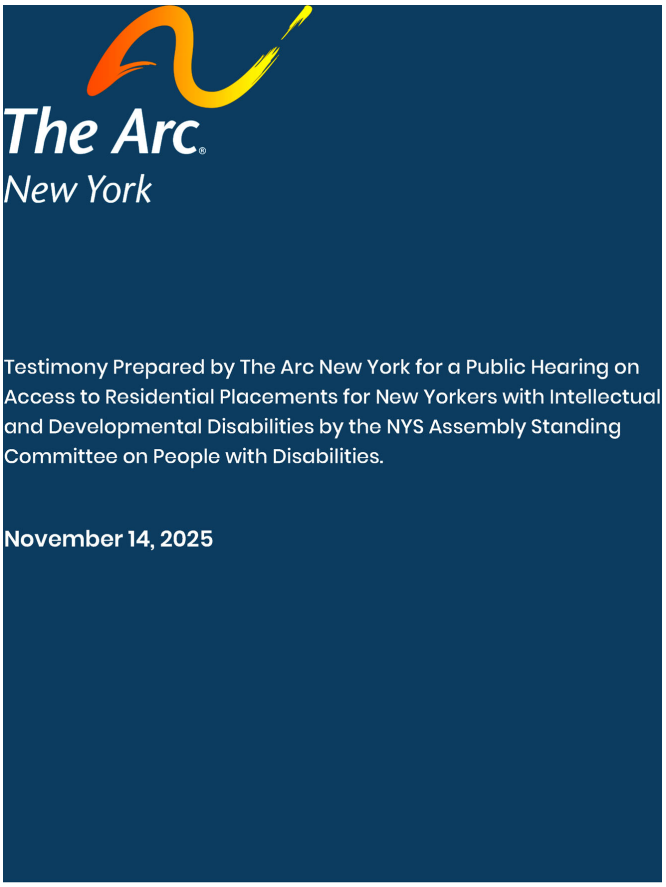
[11] Heller, T. "People with Intellectual and Developmental Disabilities Growing Old." *Impact*, Winter 2010. Retrieved from: https://publications.ici.umn.edu/impact/23-1/people-with-intellectual-and-developmental-disabilities-growing-old-an-overview. Accessed 4 Dec. 2025.

(H.R.6137[12], S.3211[13]) or similar legislation, which requires the Office of Management and Budget to consider updating the Standard Occupational Classification (SOC) and recognizing the DSP role as a distinct profession. This leads to data collection and ideally more robust funding.

Thank you for your consideration of how to build funding and services to advance the health, independence, and inclusion of aging adults with developmental disabilities.

[12] United States, Congress, House. Recognizing the Role of Direct Support Professionals Act. Congress.gov., www.congress.gov/bill/119th-congress/house-bill/6137. 119th Congress, 1st session, House Resolution 6137, introduced 19 November 2025. Accessed 8 Dec. 2025.

[13] United States, Congress, Senate. A Bill to Require the Office of Management and Budget to Consider Revising the Standard Occupational Classification System to Establish a Separate Code for Direct Support Professionals, and for Other Purposes. Congress.gov., https://www.congress.gov/bill/119th-congress/senate-bill/3211. 119th Congress, 1st session Senate Bill S.3211, introduced 19 November 2025. Accessed 8 Dec. 2025.


The Arc
New York
Testimony Prepared by The Arc New York for a Public Hearing on Access to Residential Placements for New Yorkers with Intellectual and Developmental Disabilities by the NYS Assembly Standing Committee on People with Disabilities.
November 14, 2025

The Arc New York

The Arc New York Written Testimony

Access to Residential Placements for New Yorkers with Intellectual and Developmental Disabilities by the NYS Assembly Standing Committee on People with Disabilities.

November 14, 2025

Introduction

Assembly Standing Committee on People with Disabilities Chair Assemblyman Santabarbara, Ranker Assemblywoman Jodi Giglio and members of the committee, thank you for the opportunity to provide feedback on access to residential placements for New Yorkers with intellectual and developmental disabilities (IDD) and its impact on our field and the people we support.

The Arc New York is a family-led organization with a 75-year history working toward our mission to "provide people with intellectual, developmental, and other disabilities the ordinary and extraordinary opportunities of life." Our organization is the largest provider of supports and services for New Yorkers with intellectual and developmental disabilities in the state. With 35 operating Chapters across New York state, The Arc New York supports more than 60,000 individuals and families in every county of the state and employs more than 30,000 people statewide.

The parents who created our organization were among the earliest advocates for quality services and opportunities for people with IDD. In the over 75 years since our founding, we have witnessed – and at many times driven – massive transformation and progress in our field. Over those seven decades, New York has developed a robust system of comprehensive individualized services and programs that aid independence, support families, and emphasize inclusion in communities.

We have long advocated for recognition of our essential frontline staff, sustainable investment, and common-sense policy. For over a decade preceding the current administration, that call went largely unheard. Governor Hochul has put forth new investments every year under her tenure, which have demonstrated a renewed recognition of the needs of New Yorkers with IDD. While these investments are a start, significant needs remain to right our system after years of neglect.

The Arc New York provides advocacy, residential supports, day services, employment programs, respite services, education and clinical care for New Yorkers with IDD. Today, we face a crisis of access to safe, appropriate, and person-centered residential placements. Based on voluntary provider data and estimates, thousands of individuals and families remain on waiting lists—often for years—because our system lacks the workforce, funding, and infrastructure necessary to meet their needs.

Acknowledgment of Support and Existing Barriers

According to the Office for People with Developmental Disabilities (OPWDD) Administrative Directive Memo 24-ADM-03, the residential placement process "is designed to facilitate sustainable, equitable, and accessible housing and residential supports...and to ensure availability of services for those in greatest need." We genuinely believe OPWDD shares our goals and the goals of people and families to find appropriate residential supports for New Yorkers with disabilities.

OPWDD is fully aware of the challenges around the current residential placement process and its barriers. They have taken steps to begin to address it by including significant additional rate investments at the end of 2024, technical assistance and support for behavioral challenges of people currently supported in voluntary residences, amendments to its Certified Residential Opportunity process, and additional payments offered to providers to support placement of individuals off the Residential Needs List.

The current administration and OPWDD leadership have demonstrated their commitment to improving supports for New Yorkers with IDD. The Governor and legislature have made investments after more than a decade of stagnant funding, and the Commissioner is fully engaged and collaborative, working tirelessly to identify and address operational concerns.

We deeply appreciate both the investment and the partnership.

But the reality remains: We are failing to meet the needs of thousands of New Yorkers with IDD who require support in certified residential placement. The residential placement process needs modernization and reform and our care system continues to need meaningful and sustained investment.

Overview of Challenges Facing Residential Access

Thousands of New York state citizens with IDD are waiting for placement in a community residential setting, and many are in emergency/immediate need. The state has not provided an adequate way for families to plan when providing care at home becomes difficult or impossible. People with IDD and their families face a long and uncertain placement process, without a clear understanding of that process or the extent of their wait—and while thousands await suitable placements, many existing openings go unfilled.

Ongoing staffing challenges limit our ability to safely support people with complex medical and behavioral needs, and we have inadequate resources to upgrade or modify homes limit our ability to offer suitable settings for all people in need of placement.

In practice, most placements occur through emergency referrals. This makes it nearly impossible to ensure people are placed in the most appropriate, least restrictive home environment, and limits their choice in their own housing and the opportunity to achieve as much independence as possible.

The current residential placement process results in unnecessary long-term vacancies in the voluntary sector, causing significant and unsustainable deficits for providers, and leaving thousands of people without the residential support they need.

The systemic issues with access to residential placement fall into three main areas: transparency, flexibility, and resources.

Transparency

It is important to note that a person can only be considered for residential services after all options for supporting them in their current home or another non-certified setting have been explored, documented, and exhausted. A person is only added to

the Certified Residential Opportunities (CRO) list if the state determines their needs cannot be met in an alternate setting.

There is currently no way for providers to access the complete CRO lists without request from their Developmental Disability Regional Office (DDRO). Statewide and regional data on residential need is not shared regularly or openly.

The full scope and number of people currently awaiting residential placement, or how long they have been waiting and information about individual demographics and need is inconsistently available and at times incomplete and/or unclear. We also do not know the number or characteristics of residential vacancies available across the state.

We estimate that there are approximately 5,000 people on the Residential Needs list today, and approximately 2,000-3,000 residential vacancies are available at providers across the state. However, we have no way of verifying the number of people on the list, and that is a big part of the problem. Without a clear understanding of these demographics, we cannot develop a unified strategy to address the need that exists today, or the anticipated need for the future. We would support legislation that requires OPWDD to report data on the number of people on the Residential Needs list, their demographics, support needs, time on the list, and region where they reside or are seeking placement.

Flexibility

When people are placed on the list, they are assigned a need level: Emergency Need, Substantial Need, or Current Need. People in the emergency need category are in immediate crisis. They have no stable place to live, are at imminent risk of homelessness, or face urgent threats to their health and safety or the safety of others. These people require immediate placement to ensure their basic safety and care.

People in the Substantial Need category are at rising risk of crisis. Their caregivers may be increasingly unable to meet their support needs, or risk to their safety or the safety of others is escalating. Placement of people in the Substantial Need category prevents these situations from deteriorating into emergencies.

People in the Current Need category are ready and waiting for certified residential placement, but do not face imminent danger. These are the people our system is

intended to plan ahead for — ensuring smooth, person-centered transitions before crisis hits.

We fully recognize the importance of prioritizing Emergency Need. There is no question that people cannot be left in crisis situations. However, what should be a proactive, planned system for residential care has become entirely crisis-driven.

To find placements, providers are sent residential referral packets selected by their DDRO or by provider request. Providers then review the profiles to determine if they can appropriately support that person in one of their open residential placements.

If no suitable placement is available, it is not because providers do not want to support them. Often, the care needs and behaviors of the people referred for placement are not compatible with available opportunities. The vacancy may be in a two-story home, and the person uses a wheelchair. It may be in a home of all older women, and the new resident is a young man. Or, a provider simply may not have the staff or resources to meet individual's specific or complex needs. These are reasons why a provider may not be able to support the individual, but the opening also has to be desirable and appropriate from both the family and the individual's perspective as well.

We strive to place as many people as possible in the most appropriate setting. The safety and well-being of the people we support is of utmost importance.

Often, people on the Emergency Need list require complex medical care or intensive behavioral interventions. It is simply more challenging to find appropriate placements for people with extremely high needs, but in many cases, the only referrals a provider receives are for people on the Emergency Needs list.

There have been recent improvements to this process, and providers are sometimes able to place referrals from the Substantial Need list. But it is critically important to understand that people from the Current Need list are rarely referred to providers for residential placement. These are people whose support needs the state has determined can *only* be met in a residential setting. But unless someone is in or nearing crisis, we rarely even consider a placement for them.

In some cases, we have vacancies that could be a wonderful fit, but without flexibility to fill them with people who are not in immediate crisis, the bed stays vacant, and people in the current need category continue waiting – indefinitely – for a home.

This represents a significant breakdown in our residential service system.

Resources

You have heard for years that our system is not adequately or sustainably funded. We went more than a decade with no increases – zero.

That is changing, and we appreciate it. Recent investments have demonstrated a positive shift in the state's commitment to people with disabilities. But to date, those investments don't even fully compensate for inflation over the past five years. We still do not have the resources needed to fulfill our mission for all New Yorkers with disabilities.

Fundamentally, there are not enough residential placements available to meet the needs of people waiting for services. Yes, we have vacancies, but if we filled them all tomorrow, thousands of people would still be waiting for homes.

The state needs to make capital investments to expand residential opportunities, and continue to make workforce investments to make sure we have staff to operate them.

We have finally been able to start raising wages that were stagnant for years, but direct care and clinical staff are still woefully undercompensated, and providers are not competitive in the employment market.

We need consistent staffing to operate homes. To safely support people with high needs, we need tenured direct care and clinical staff who can deliver complex medical care and implement challenging behavior plans.

Providers are sometimes hesitant to take on people with extremely high support needs, because they cannot be confident they will have the resources necessary to sustain those supports, or that alternatives will be available if a placement become untenable. Guaranteeing high-needs funding to align with the cost of high-needs care would allow us to fill more vacancies and support more people.

Nonprofit providers are not the only ones who are under-resourced. DDROs are responsible for managing residential referrals and maintaining an updated CRO list. They do so with minimal staff, using antiquated systems. They too need adequate resources to fulfill their role, and modern electronic solutions for managing a complex system of care.

Recommendations

So how do we do better? By improving transparency, flexibility and resources.

We are currently requesting a 2.7% Targeted Inflationary Increase (TII) in the New York state budget to correct for inflation over the past year and ensure funding accounts for the increased cost of living and providing services.

We have proposed a Careforce Affordability Initiative to support recruitment and retention with opportunities for affordable housing, childcare and healthcare for direct care staff. We have also put forward a Capital Funding and Infrastructure Plan to maintain and modernize programs and facilities, which would improve outcomes and save money.

Beyond our budget requests, we must consider:

- Expanding access to step-down facilities where people with immediate psychological and behavioral challenges can receive intensive support until they can be effectively supported by a community provider,
- Enhancing the role of OPWDD State Operated programs as the "provider of last resort," to ensure a safety net is available if a placement proves inappropriate.
- Examining the high-needs funding process to ensure providers are appropriately paid for intensive services,
- Improving the clinical competency of voluntary providers to handle more challenging referrals,
- Developing an efficient electronic management system that allows for partnership between nonprofit providers and the state, including access to complete, real-time information about people in need of placement, and
- Improving transparency by requiring annual reporting on residential waitlist size, duration, and demographics. Previous attempts had been made by the legislature to address this need, but it did not advance out of committee.

Conclusion

The crisis in residential supports for people with intellectual and developmental disabilities is not a problem of isolated inefficiency—it is a systemic issue that profoundly impacts thousands of New York families. Addressing this requires

sustained commitment to fair funding, workforce stabilization, transparent data, and person-centered planning.

New Yorkers with developmental disabilities have a right to a home and supports, which respect their dignity, independence, and choice. New York has a legal and ethical responsibility to provide those supports.

The Arc New York urges OPWDD to continue to partner with the provider community, governor and legislature in exploring strategies to address the needs of people in crisis, and to prevent others from slipping into crisis by better meeting current and future need.

We understand this is a complex topic, and we have additional recommendations. By holding this hearing, you have demonstrated your interest in improving access to residential services. We believe we can be strong partners in an ongoing dialogue about creative solutions to address these issues and better meet the needs of New Yorkers with disabilities, and we encourage you to continue this conversation.

The Kennedy Willis Center
ON DOWN SYNDROME

December 8, 2025

Dear Chair and Members of the Committee,

I am writing to share the perspective of our agency on the importance of programs that allow people with disabilities and older adults to participate fully in their communities. These initiatives are not simply services; they are lifelines that foster dignity, independence, and belonging.

Community-based programs—whether they provide accessible transportation, inclusive recreational activities, or support for independent living—help ensure that older adults and individuals with disabilities remain active contributors to society. They reduce isolation, improve health outcomes, and strengthen the social fabric of our neighborhoods.

Investing in these programs is an investment in the values of equity and respect. When older adults and people with disabilities are supported to live, work, and thrive in their communities, everyone benefits. Families experience less strain, local economies grow, and communities become more compassionate and resilient.

It is important to recognize that adults with intellectual and developmental disabilities (I/DD) are living longer than ever before. Advances in medical treatment, improved living conditions, strong caregiver supports, and the growth of autonomy and self-advocacy efforts have all contributed to this increased longevity. As a result, the need for continued and expanded community-based programs for older adults will be critical for years to come. These programs must evolve to meet the unique needs of aging individuals with I/DD, ensuring they can thrive with dignity and independence throughout their lifespan.

I urge the Committee to continue championing policies and funding that sustain and expand these vital programs. By doing so, you affirm the principle that every individual—regardless of age or ability—deserves the opportunity to participate fully in community life.

Thank you for your leadership and for collecting these stories and statements. I am grateful for your commitment to ensuring that our nation remains a place where all people can live with dignity and purpose.

Brittany Goodrich

Brittany Goodrich

Director
The Kennedy Willis Center on Down Syndrome

I have 45 years needing healthcare to live! I'm a C56 quadriplegic! Paralyzed from the chest down, half my arm function, little hand function! I broke my neck playing Box Lacrosse in Brockport NY! This gutting of healthcare is a slow genocide! I wouldn't last a month without healthcare! Also I worked, paid taxes, paid into healthcare, had a great life because I had healthcare! Ppl deciding to gut healthcare haven't got a clue about the consequences! They don't ask those of us who do know! Without HCBS I would not last long! Being forced against my will into a Nursing Home might crush my spirit! Cuts to services, care, equipment , supplies would cause bankrupcy then chaos! This Admin has some really sick plans for America! Eugenics and population reduction not a far fetched concept to these new leaders! So disappointed the Country has turned on healthcare as it has!

Bart Brophy IBART



City Harvest provides nutrition education at NORC site through SNAP-Ed funding. The July 2025 HR1 spending bill that was signed into law cuts all USDA funding for the program. Through our work at NORC sites and older adult centers, we can attest to the incredible resources that these facilities provide to seniors. Not only do they keep seniors active, but they connect them with their community and with external resources from organizations like City Harvest. Below are 2 testimonials from seniors who participate in our programming:

Testimonials

"The City Harvest Nutritional Education and Cooking Program is excellent for Older Adults. These programs provide community and insight about accessing healthy, low cost meals/dishes. Majority of Older Adults in my centers live under the poverty line and their neighborhoods do not provide too many healthy options. These programs brought awareness, education and enjoyment to our Older Adults. My older adults enjoy the educators, the connection with them was great and they are willing to try eating healthier. We look forward to having this program services our older adults." - **Joseph Dupree, Program Coordinator, Fort Greene Council**

"My name is Reginald Umpthery and I work for Fort Greene Council's Willoughby Older Adult Club. We have partnered with City Harvest for a couple of years and it has been amazing. The older adults really enjoy each session. This workshop had all of my members in the class engaged and asking questions, many of which is from their experience with nutrition. City Harvest has shown my member how to eat healthy and the benefits and consequences of each meal they eat. It eliminated the age old myth that you can't eat healthy on a budget. Many of my members speak about how this class has changed their life for the better and how they tried out the meals that were taught. I hope this partnership continues and City Harvest is doing a great deal for our community." **- Reginald Umpthery, Fort Greene Council's Willoughby Older Adult Club**

About City Harvest

City Harvest is New York City's first and largest food rescue organization. We rescue nutritious, high-quality food that would otherwise go to waste and deliver it for free to hundreds of food pantries, soup kitchens, community partners, and our own Mobile Markets® across the five boroughs. In response to the urgent and ongoing demand for food assistance and a commitment to sustainability, this year we will rescue more than 86 million pounds of food and deliver it to New Yorkers experiencing food insecurity. With deep connections to the communities where we work and with a focus on localized investment, City Harvest is dedicated to strengthening our network of agency partners and the local food system through capacity building, advocacy, and nutrition education. Through our food rescue model, we support environmental health—this year, we will prevent the equivalent of more than 25.4 million kilograms of CO2 from entering the atmosphere—while providing New Yorkers with the food they need to thrive. City Harvest is recognized as a leading equity-driven organization and has been named one of America's Top

100 Charities by Forbes. Since our founding in 1982, we have rescued more than one billion pounds of food and provided it for free to our neighbors in need.



Diana Vilá, Rego Park NY

The photo shows a smiling, olive-skinned woman with short salt-and-pepper hair and hazel eyes, wearing a turquoise shirt and holding a small black and white dog.

Diana Vilá lived in a large institution in New York City called an "adult home" that housed primarily people with mental health disabilities. After more than twelve years there, she was able to transition to her own apartment with the services she needs due to an ADA class action settlement between individuals with mental health disabilities and the state of New York. Diana provided these remarks at a recent briefing:

Individuals like myself with severe mental illness and like my fiancé Ruberto and friends with additional physical and developmental challenges are dumped into institutions and left to languish and die. An adult home never felt like my home.

Like many residents, I longed to escape but didn't have enough money for a rental deposit or to pay New York City rent. With help of my fiancé Ruberto, and my important special friend Tasha [a service dog], it is possible for me to be here today. My good friend likens her disability to wearing a heavy blanket as she walks through her day and her life. It is exhausting and invisible to others. I would like to add to the metaphor. The blanket is very cold. It covers my brain and clouds my eyes. Many with mental disabilities tend to hide it very well. Most of the time.

Some days I struggle very hard and cannot even access my vocabulary. On other days I work hard at my full mental capacity. I'm driven and focused. On good days I give 150% not only to move forward and get ahead, but to make up for the days when I cannot.

Leaving the community college where I worked 20 years was not a good thing for me. I had a job where I felt fulfilled, creative and knew that I made a difference every day. I felt fulfilled and honored to be there. But I fell far and hard when I left. I didn't want to struggle any more. I lost hope and purpose. Living in the adult home was a sad life. Two people in a small room barely big enough for the furniture. I felt broken and defeated.

It wasn't always safe to socialize outside the room and the food provided was barely edible. Some residents were overmedicated while others were out of control, fighting and yelling. The police came to the home often. This atmosphere was not kind to my disability.

Tending to my plants in the small window helped me escape the darkness in my mind and the chaos outside the room. There was rampant neglect in the adult home. My partner and then-roommate Jose died of complications from diabetes and renal failure. I noticed my health had begun to decline also.

When I met Ruberto, my fiancé, he traveled on two buses in a manual wheelchair a great distance to pull me out of my grief. I helped him obtain a power wheelchair like I did for Jose and others.

With greater mobility and independence we were able to go on longer trips to the movies on discount days once a month, to free museum days, in the park and window shopping at the mall. I helped him get into training that enabled both of us to work at CIAD nonprofit organization dedicated to empowering adult home residents. For eight years in this role of peer advocate, I helped residents fight for their rights and prepare for independent living through well-received workshops.

I jumped at the chance to live on my own again with support, with support, very important. These two court cases made it possible for us to finally move into a wheelchair-accessible and bright sunny apartment after eight years on the list. Now Ruberto can move freely throughout the space, cook and help manage our affairs with relative ease.

For me, the bright, open environment has been transformative. My home is filled with flowering plants that lift my spirits and offer a sense of peace and renewal each day. Watching cherry tomatoes and seedlings grow makes me so happy. On restless nights when insomnia keeps me awake, I find solace and watching the sunrise from my windows, a reminder of new beginnings, as the seedlings are. My disability knocks me down but doesn't have to define my potential. With help and support, I keep getting back up.

Now I have choices, responsibilities and freedoms that I wasn't allowed in the adult home. Now I can afford to eat better. I have lost 40 pounds. I fell far when I got really sick but I hope to return to teaching and counseling. I want to return to supporting students through their challenges of getting a degree in the field of their choice and creating better lives for themselves and their families. With the right support, I can live independently in a safe environment in my own home, not an institution where my rights and dignity are stripped away. I can make a positive contribution to society. But the right support is critical.

Statement for US Senate Special Committee on Aging

12/03/2025

My name is Sue Ruff. I am a person who has disabilities. I am also the parent of a person with multiple disabilities. I grew up with a brother who was born with developmental and heart conditions. As my parents aged, they, too, had to deal with health issues that affected their lives. Disability touches everyone at some point.

I have worked at an Independent Living Center for more than thirty years. I work forty hours a week. My first job at the ILC was in supported employment. I helped people (that many thought could not work), find and keep jobs. I then transferred to a program at our center that worked with children birth to five and their families. And after a few years I was asked to work on disability rights, which is still my current job.

Home and Community Based Services (HCBS) keep people with disabilities in their own homes and communities, in integrated and inclusive settings. My brother was born in 1959, before the passage of 94-142 (IDEA). Doctors told my parents to place him in a nearby institution and tell the rest of the family he had died. They told the doctors NO. The pediatrician the rest of us children saw was generally unwilling to take care of my brother. There were few options for his education and my parents had to fight very hard to get him into a program run by a not-for-profit. He wanted to go to school with his brothers and sisters, but that was not allowed. And my father's employer would not pay for any health insurance for my brother, so his doctor's visits and medicines were paid for by my folks.

My dad was a farmer and a factory worker. My mother was a teacher who left the field to take care of her six children, mostly to care for my disabled brother. My father gave five years of his life in the Pacific theatre in WW II. He was a naturalist who could identify trees, plants, bird songs, animal tracks. He was also an athlete who could have played professional baseball but had to help on his family's farm when he was a teen. My mother never really stopped teaching and often helped the children of friends in our small town, when those children struggled with schoolwork.

Our next-door neighbor was a hospital CEO and he would not let the hospital and doctors bill my parents when my brother was hospitalized at age 12. My brother died of congestive heart failure in 1972. My brother was dearly loved and cared for by our family during a time when so many children were placed in state institutions. He was a great teacher, too. He taught love.

My daughter has six disabilities. She lives in her own apartment and has staff support for about 50-60 hours a week. The other hours of support that she needs are provided mostly by me, but also by other family members. HCBS enables her to be independent

and to participate actively in her community here in the Southern Tier of NY. She attended a local school (was a Girl Scout, choir member, and cheerleader while working on her education in inclusive classes). She was employed for a few years, but a brain injury in her early twenties severely limited her employment prospects. She volunteers, sings in a local choir, goes to the Y, plays with her nieces, and spreads a lot of love around. She is aging. So am I.

Over the decades I have known very many people who were placed in institutional settings. Every one experienced abuse or neglect or both. For those that were helped by the Independent Living Center or by HCBS, life changed dramatically. Trauma from abuse or neglect never goes away. But HCBS opens the doors to real life opportunities.

When people with disabilities live independently with supports and services, they have the chance to contribute to the fabric of our society, to be valued and to share their individual gifts. We are not asking for charity. We are YOUR family and YOUR neighbors and OUR LIVES are important. We are YOUR COMMUNITY.

December 03, 2025

Senator Gillibrand:

Please take the time to read this presentation in its entirety. Despite my advanced age (88 y/o), I continue to have the mental acuity to form intelligent opinions, and I do so on behalf of 61M Americans.

I am a paraplegic with multiple deficits — I have very limited use of my arms and legs due to multiple joint replacements. I am able to transfer from my electric recliner to my power wheelchair, two pieces of Durable Medical Equipment (DME), on which I am totally dependent. I can toilet myself and manage to get to bed. Almost everything else is done by my caregivers.

For appoximately the last two years, I have been functioning under the auspices of the Centers for Disability Rights (CDR) and the Nursing Home Transition and Diversification (NHTD) Agency. I cannot imagine my life without the boost I get from participating with these organizations, since paraplegia is daunting and I need twelve (12) hours of care per day. All Metro is an entity that provides in-home care for me, and to date they have offered two truly stellar young people to be caretakers for me. They are energetic, intelligent, trustworthy, empathetic. I cannot imagine what my life would be if it were not for the intervention by these young women. I COULD NEVER GET THIS LEVEL OF INDIVIDUAL CARE AT A NURSING HOME! They make it possible for me to participate in forays for shopping and sometimes out to lunch. While these events are few and far between, they are events and they allow me to occasionally participate as a regular member of society. A leading cause of depression is the sense that one is not as equal in standing as their peers. I truly feel so blessed and during this season of Thanksgiving, it is an appropriate time to voice my pleasure with the services I have and do receive.

For me it was as though someone threw a light switch, and my life went from active and overwhelming . . . busy beyond comprehension to being in a wheelchair; becoming a paraplegic all while trying to raise four small children. As aging took its toll on my battered body, the personnel from various agencies stepped up to the plate and guided me through the multiple necessary processes to glean help where it was needed. Due to that, I have food supplementation (SNAP), which allows me to participate in a better and healthier diet. With SNAP benefits, I can afford to purchase fruits and vegetables that were heretofore out of my budget's range. However, my SNAP benefits were recently cut 27%. I believe my income went up by $5./month and my benefits were cut $77./month. This was done prior to the government shutdown. Additionally, transportation is provided for medical and dental appointments.

Even though I made my living as a wordsmith prior to retirement, verbiage escapes me when I try to express how it felt to become disabled, and more importantly, how freeing it was to receive a hand up when I felt so desolate!!! While I can spew accolades of appreciation for what is, I must hasten to point out that so much more is needed. One of the fastest growing demographics in the United States of America is the elderly and disabled, second only to those of Spanish descent. Transportation for those who can no longer operate a motor vehicle is borderline impossible, especially if one needs a power wheelchair. The Medical Answering Service (MAS) is an entity supposed to understand in finite terms what is required and provided for the elderly and infirm — MAS does not know!!! When I posed the query: "Are the Ameratrans vans ADA compliant?" The MAS response was, "It's not their job to assure compliance." My efforts to find an answer to this question has been met with substantial resistance. As a participant in the transportation program, and being a paraplegic, I can tell you firsthand, the Ameratrans vans are NOT safe and I have been injured by one of the Ameratrans drivers, due to his explosive temper and his inadequately equipped van!!!

I desperately needed an automatic door opener because when you need one hand to operate a power wheelchair, and you need one hand to carry groceries, mail, etc., oops!!! You are out of hands! I was growing antsy about the wait (three years and holding), when I was informed by my coordinator, Melanie Hillman, that "They were working on one door opener for another client, and when they get that finished, they will begin to work on one for me." The manager where I reside, Kevin Wood, having overheard the exchange said, "That's ridiculous, I will provide a door opener for you!" Within a matter of days, an automatic door opener was delivered and installed at my apartment entrance.

In November the back of my electric recliner just gave out, and my spine began to creep down into the hole created between the seat and back of that chair. There was some sort of mixup and Medicare refused to financially assist me with the purchase of a new electric recliner, stating that, "FAILED UPHOLSTERY IS NOT JUST CAUSE FOR REPLACEMENT. Truly, I was flummoxed! I needed this piece of DME. Thus, I paid out-of-pocket just under $3,000 for it. I spend 90% of my waking hours in this recliner, so comfort is critical. At some point, I will do battle with Medicare, but at this juncture, I do not have sufficient energy.

Medicare demands a five (5) year period of time before replacing any DME items. My power wheelchair is 3.5 years old and has dismally failed me. The seat of the chair fits into a tube on the chair base, but it has become loose over the years. There is no provision to tighten it, so the seat now rotates over the base. This is dangerous when I try to transfer from my recliner to the wheelchair. In addition, the arms of the chair wobble from side to side, causing another safety issue when transferring. The wheelchair is currently unsafe.

In conclusion, since I am so limited, the help I get from CDR, NHTD, and ALL METRO is critical for my survival. However, there is so much more that could be done for the elderly/disabled. It is also abysmal that it took me two to three years of research, phone calls, meetings, etc. to get this all set up and working.

Thank you for your time.

Lynn Dejaiffe
110 Creekside Drive
Apartment #337
Painted Post, NY On 14870-9238
Lynn.Dejaiffe@gmail.com
Telephone: (607)973-2206



Korean Community Services of Metropolitan New York, Inc.
203-05 32nd Avenue Bayside, NY 11361
www.KCSNY.org
(718) 939-6137
info@kcsny.org

December 8, 2025

Dear Senate Special Committee on Aging,

We are writing about the importance of community living for older adults and people with disabilities. The writings below are from actual clients and staff who have relationships with KCS. KCS have many departments and out of all departments, 5 different departments are sharing their stories.

Thank you.

Sincerely,

Joon Soo An
Administration Officer
Korean Community Services of Metropolitan New York, Inc.

HEADQUARTERS (ADULT DAY CARE EDUCATION / IRR IMMIGRATION & LEGAL SERVICES PUBLIC HEALTH AND RESEARCH CENTER / WORKFORCE DEVELOPMENT)

203-05 32nd Ave, Bayside, NY 11361
Tel: 718-939-6137

OLDER ADULT CENTER

42-15 166th St, Flushing, NY 11358
Tel: 718-886-8203

37-06 111th St, Corona, NY 11368
Tel: 718-651-9220

633 W 115th St, New York, NY 10025
Tel: 718-886-8203, 347-927-0124

PUBLIC HEALTH AND RESEARCH CENTER (1)

115 5th Ave, #705, New York, NY 10016
Tel: 212-463-9685

2460 Lemoine Ave, #400F Fort Lee, NJ 07024
Tel: 201-364-8375

103-04 39th Ave, #103, Corona, NY 11368
Tel: 917-396-4149

PUBLIC HEALTH AND RESEARCH CENTER (2)

410 Broad Ave. #201, Palisades Park, NJ 07650
Tel: 201-429-2866

35Sb 159th St. #2nd Floor, Flushing, NY 11358
Tel: 718-939-6137

WORKFORCE DEVELOPMENT

325 West 38th St. #1107, New York, NY 10018
Tel: 929-300-8630, 929-341-8302

410 Broad Ave. #201, Palisades Park, NJ 07650
Tel: 201-429-2866

MENTAL HEALTH CLINIC

42-16 162nd St. 2FL, Flushing, NY 11358
Tel: 718-366-9540

410 Broad Ave. #201, Palisades Park, NJ 07650
Tel: 201-429-2866

IMMIGRATION & LEGAL SERVICES

410 Broad Ave. #201, Palisades Park, NJ 07650
Tel: 201-446-5264

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Education Department – Teresa Baik, Director of Education

We would like to share the stories of two of our students to illustrate the impact of our ESOL programs.

The first student began experiencing early symptoms of Alzheimer's disease after retiring from his job in Korea. He later moved to the United States with his family, but spending most of his time at home in an unfamiliar environment led to feelings of depression and isolation, which also placed significant stress on his family. To overcome these challenges, he decided to begin studying English. With the support of his family, he contacted several community centers and libraries but was unable to find a suitable program. Eventually, he learned that KCS was offering ESOL classes, and he enrolled immediately. He has now been attending our classes consistently for about a year and a half. Although speaking and writing remain difficult for him, he participates actively and demonstrates strong motivation to learn. Over time, he has become more comfortable with his teacher and classmates and has gained renewed energy and confidence in his daily life. While he still spends most of his time at home, attending ESOL classes has given him opportunities to go out and expand his connection to the community. In particular, he now takes public transportation by himself twice a week to attend class, which has significantly increased his confidence. He has also shared that the relationships he has built with his teacher and classmates provide meaningful emotional support.

The second story is regarding one of our older adult students with significant mobility challenges. In the past, whenever she needed to go to the hospital or attend physical therapy, she relied on transportation provided by her insurance and always needed someone's help or had to go through a Korean-speaking staff member, which was cumbersome. After continuously attending our ESOL classes, she has been able to handle these calls and appointments on her own, which she has found to be rewarding and liberating. This experience has not only given her the flexibility/freedom to move around but also a strong sense of confidence in her ability to solve problems on her own. Seeing the results firsthand has increased her motivation/dedication to continue learning English. In addition, after a year of taking ESOL classes at KCS, she is now able to communicate with her Chinese and Spanish-speaking classmates. Being able to socialize



with peers from different backgrounds has not only brought new energy into her social life but it has added fuel to her motivation for learning English.

Although there are numerous stories like the two that we mentioned, these two student stories clearly highlight that the KCS ESOL program goes beyond just language instruction. It directly supports our older adult learner's' independence, social engagement, and overall quality of life. KCS' Education Department is committed to continuing this work, helping students gain confidence, connection, and vitality through learning and meaningful experiences.

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203-05 32nd Ave,
Bayside, NY 11361
Tel: 718-939-6137

OLDER ADULT CENTER

42-15 166th St,
Flushing, NY 11358
Tel: 718-886-8203

37-06 111th St,
Corona, NY 11368
Tel: 718-651-9220

633 W 115th St
New York, NY 10025
Tel: 718-886-8203,
347-923-0124

PUBLIC HEALTH AND RESEARCH CENTER (1)

315 5th Ave #705,
New York, NY 10016
Tel: 212-463-9685

2460 Lemoine Ave,
#406P, Fort Lee, NJ
07024
Tel: 201-364-8375

103-04 59th Ave, #103,
Corona, NY 11368
Tel: 917-390-4149

PUBLIC HEALTH AND RESEARCH CENTER (2)

410 Broad Ave. #201,
Palisades Park, NJ 07650
Tel: 201-429-2866

3556 159th St. #2nd Floor,
Flushing, NY 11358
Tel: 718-939-6137

WORKFORCE DEVELOPMENT

325 West 38th St.
#1107, New York, NY
10018
Tel: 929-500-8630,
929-341-8302

410 Broad Ave. #201
Palisades Park, NJ 07650
Tel: 201-479-2866

MENTAL HEALTH CLINIC

42-16 162nd St. 2FL,
Flushing, NY 11358
Tel: 718-366-9540

410 Broad Ave. #201,
Palisades Park, NJ
07650
Tel: 201-429-2866

IMMIGRATION & LEGAL SERVICES

410 Broad Ave. #201,
Palisades Park, NJ 07650
Tel: 201-446-5268

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Mental Health Clinic (MHOTRS) – Yuna Youn, Clinic director

Thank you for the opportunity to share my perspective on the vital importance of Home and Community-Based Services (HCBS), Centers for Independent Living (CILs), and other services and supports, such as those that help people thrive in places like educational and work settings for older adults and people with disabilities. Korean Community Services offers a range of services, the largest of which are for the aging population. Working closely with our Older Adult Centers, the KCS Mental Health Clinic, a MHOTRS Clinic licensed under New York state, has an informed perspective on the barriers and needs of the most vulnerable older adults in the community. This insight is obtained through ongoing, culturally and linguistically responsive care and clinical treatment. Counseling allows clients to develop insight into their needs and to share in their own words how they can receive support beyond their outpatient care.

Our clinic provides comprehensive psychiatric and counseling services alongside community mental health outreach to hundreds of older adults, including many who live with serious mental illness, cognitive decline, functional limitations, and complex social circumstances. For these individuals, clinical care alone is not enough. What allows them to remain stable, avoid hospitalization, and continue living in the community they know is the network of Home and Community-Based Services—skill-building, peer support, caregiver assistance, respite, case management, education and employment support, and in-home and community-based interventions.

HCBS fills the gaps between medical or psychiatric treatment and the day-to-day realities of living with disability or aging. HCBS workers help older adults use public transportation safely, manage medications, prepare meals, maintain routines, and stay socially connected. Research and qualitative reports indicate that these supports are essential to preventing psychiatric decompensation, medical crises, or early institutionalization. From a policy standpoint, it is therefore more fiscally beneficial to ensure services like HCBS and CILS are well supported and resourced. Beyond costs, these supports will work to address older adults' isolation, language barriers, stigma around mental illness. HCBS providers who meet them where they are—in their homes, their neighborhoods, and their daily lives—build trust in ways that traditional clinic settings alone cannot. This culturally grounded engagement allows our clinicians to collaborate more effectively with families and keep older adults connected to their communities, churches, senior centers, and support networks.

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203-05 32nd Ave,
Bayside, NY 11361
Tel: 718-939-6137

OLDER ADULT CENTER

42-15 166th St,
Flushing, NY 11358
Tel: 718-886-8203

37-06 111th St,
Corona, NY 11368
Tel: 718-651-9220

633 W 115th St,
New York, NY 10025
Tel: 718-886-8203,
347-923-0124

PUBLIC HEALTH AND RESEARCH CENTER (1)

315 5th Ave, #705,
New York, NY 10016
Tel: 212-463-9685

2460 Lemoine Ave,
#400F Fort Lee, NJ
07024
Tel: 201-364-8375

103-04 39th Ave, #103,
Corona, NY 11368
Tel: 917-396-4149

PUBLIC HEALTH AND RESEARCH CENTER (2)

410 Broad Ave. #201,
Palisades Park, NJ 07650
Tel: 201-429-2866

35Sb 159th St. #2nd Floor,
Flushing, NY 11358
Tel: 718-939-6137

WORKFORCE DEVELOPMENT

325 West 38th St.
#1107, New York, NY
10018
Tel: 929-300-8630,
929-341-8302

410 Broad Ave. #201,
Palisades Park, NJ 07650
Tel: 201- 479-2866

MENTAL HEALTH CLINIC

42-16 162nd St. 2FL,
Flushing, NY 11358
Tel: 718-366-8540

410 Broad Ave. #201,
Palisades Park, NJ
07650
Tel: 201- 429-2866

IMMIGRATION & LEGAL SERVICES

410 Broad Ave. #201,
Palisades Park, NJ 07650
Tel: 201- 446-5268

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As our population ages, and as more older adults express their clear preference to remain in their homes, HCBS, CILS, and related services must be strengthened, expanded, and funded sustainably. Without HCBS, our mental health system becomes reactive rather than preventative; families shoulder impossible burdens; and older adults lose the very autonomy that defines their quality of life.

Community living is not simply a policy goal—it is a cornerstone of human dignity. HCBS is what allows older adults and people with disabilities, including those with mental health conditions, to remain active members of their communities, to maintain their cultural identity, and to live with choice and purpose.

Thank you for recognizing the critical role HCBS plays in our aging and disability systems, and for elevating the voices of those of us who serve on the front lines of community-based care. I urge continued investment in these programs so that older adults and people with disabilities—across all communities, including those historically underserved—can thrive in the places they call home.

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203-05 32nd Ave,
Bayside, NY 11361
Tel:
718-939-6137

OLDER ADULT CENTER

42-15 166th St,
Flushing, NY 11358
Tel: 718-886-8265

37-06 111th St,
Corona, NY 11368
Tel: 718-651-9220

633 W 155th St
New York, NY 10025
Tel: 718.886.8265,
347-923-0124

PUBLIC HEALTH AND RESEARCH CENTER (1)

315 5th Ave, #705,
New York, NY 10016
Tel: 212-463-9685

2460 Lemoine Ave,
#400F Fort Lee, NJ
07024
Tel: 201-364-8375

103-04 39th Ave, #103,
Corona, NY 11368
Tel: 917-396-4149

PUBLIC HEALTH AND RESEARCH CENTER (2)

410 Broad Ave. #201,
Palisades Park, NJ 07650
Tel: 201-429-2666

35Sh 159th St. #2nd Floor,
Flushing, NY 11358
Tel: 718-939-6137

WORKFORCE DEVELOPMENT

325 West 38th St.
#1107, New York, NY
10018
Tel: 929-300-8630,
929-341-8502

410 Broad Ave. #201
Palisades Park, NJ 07650
Tel: 201- 479-2666

MENTAL HEALTH CLINIC

42-16 162nd St. 2FL,
Flushing, NY 11358
Tel: 718 366 9540

410 Broad Ave. #201,
Palisades Park, NJ
07650
Tel: 201- 429-2666

IMMIGRATION & LEGAL SERVICES

410 Broad Ave. #201,
Palisades Park, NJ 07650
Tel: 201- 446-5266

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Older Adult Center(OAC) Department – Helen Ahn, Managing Director

The KCS Flushing Older Adult Center (OAC) serves more than 400 older adults each day, providing culturally responsive Home and Community-Based Services (HCBS) that allow immigrant and limited-English-proficient seniors to live safely and independently in their community. Through daily hot meals, bilingual case assistance, wellness programs, and social connection, KCS Flushing prevents isolation and unnecessary institutionalization for some of the most vulnerable older adults in Queens.

One of the clearest examples of HCBS in action is Ms. Jong Soon Nha, who has been coming to KCS Flushing OAC since 2013. She is 80 years old and currently fighting stomach cancer. She had been living with her daughter and son-in-law in Georgia, but after her daughter passed away, her son-in-law forced her out of the home. With no other family in the United States, she moved to New York, stayed at a homeless shelter, and picked up plastic bottles on the street to make ends meet.

At KCS Flushing OAC, she finally found stability and support. She receives help with translation, senior housing applications, eviction issues, her permanent resident card and citizenship process, SNAP, Medicaid, and more. Despite the difficult circumstances she faces, she often brings snacks and coffee for staff, expressing deep gratitude for the Center. KCS continues to assist her with housing and her path toward citizenship.

Ms. Nha's story reflects what thousands of KCS seniors experience every year: HCBS is not just a set of services—it is what allows older adults to remain in their communities, maintain dignity, and avoid homelessness or institutional care. With culturally competent, community-based supports like KCS Flushing OAC, vulnerable seniors are able to live safely, independently, and with the connection every older adult deserves.

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203-05 32nd Ave,
Bayside, NY 11361
Tel
718-939-6137

OLDER ADULT CENTER

42-15 166th St,
Flushing, NY 11358
Tel 718-886-8263

37-06 111th St,
Corona, NY 11368
Tel 718-651-9220

633 W 115th St,
New York, NY 10025
Tel 718-886-8263,
347-923-0124

PUBLIC HEALTH AND RESEARCH CENTER (1)

315 5th Ave, #705,
New York, NY 10016
Tel 212-463-9685

2460 Lemoine Ave,
#400F, Fort Lee, NJ
07024
Tel 201-364-8375

103-04 39th Ave, #103,
Corona, NY 11368
Tel 917-396-4149

PUBLIC HEALTH AND RESEARCH CENTER (2)

410 Broad Ave, #201,
Palisades Park, NJ 07650
Tel 201-429-2866

3550 159th St, #2nd Floor,
Flushing, NY 11358
Tel 718-939-6137

WORKFORCE DEVELOPMENT

325 West 38th St,
#1107, New York, NY
10018
Tel 929-300-8630,
929-341-8302

410 Broad Ave, #201,
Palisades Park, NJ 07650
Tel 201-479-2866

MENTAL HEALTH CLINIC

42-16 162nd St, 2FL,
Flushing, NY 11358
Tel 718-366-9540

410 Broad Ave #201,
Palisades Park, NJ
07650
Tel 201-429-2866

IMMIGRATION & LEGAL SERVICES

410 Broad Ave, #201,
Palisades Park, NJ 07650
Tel 201-446-5265

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Public Health Research Center Department – Sara Kim, Senior Director of PHRC

Thank you for the opportunity to submit testimony on the essential role that community-based organizations play in supporting older adults and people with disabilities to live independently, with dignity, and in the communities they love. My name is Sara Kim, and I serve at Korean Community Services of Metropolitan New York (KCS), a nonprofit organization that has served immigrant, limited- English-proficient (LEP), and low-income individuals, their family members, and older adults for more than fifty years.

Every day, we see how preventive health care, culturally responsive outreach, and community-rooted services allow older adults to stay healthy, remain in their homes, and avoid costly institutional care. I share this testimony on behalf of the thousands of New Yorkers—many of them older Korean Americans, Asian Americans, and immigrants—whose stories illuminate the power of community living.

Story about Cancer Prevention and Well-aging: Community Cancer Screening

In October, a 69-year-old Korean American senior who smoked for more than twenty years visited our community-based mobile lung cancer screening van, which could be possible in partnership with NY Presbyterian Health System. He carried his health plan, but never screened for lung cancer despite being at risk for lung cancer. Our community health workers met the client during outreach activities at one of the Asian grocery stores, and he said that he was “too healthy” to worry about. However, we emphasized that he was eligible for lung cancer screening, which can help with early detection of lung cancer.

Through our free community-based lung cancer screenings, we connected her to a low-dose CT scan. According to the clinical provider, the scan revealed an early-stage abnormality, so the client immediately could receive the follow-up advanced diagnosis.

This is only one of hundreds of stories. Our community events routinely screen individuals who have never accessed preventive care because of language barriers, lack of insurance, or fear of the health system. Early detection has saved lives—and prevented unnecessary hospitalizations and long-term care placement.

Story about Helping Older Adults Avoid Diabetes—and Disability

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203-05 32nd Ave, Bayside, NY 11361
Tel: 718-939-6137

OLDER ADULT CENTER

42-15 166th St, Flushing, NY 11358
Tel: 718-886-8203

37-06 111th St, Corona, NY 11368
Tel: 718-651-9220

633 W 115th St, New York, NY 10025
Tel: 718-886-8203, 347-923-0124

PUBLIC HEALTH AND RESEARCH CENTER (1)

315 5th Ave, #705, New York, NY 10016
Tel: 212-463-9685

2460 Lemoine Ave, #400P, Fort Lee, NJ 07024
Tel: 201-364-8375

103-04 39th Ave, #103, Corona, NY 11368
Tel: 917-796-4149

PUBLIC HEALTH AND RESEARCH CENTER (2)

410 Broad Ave. #201, Palisades Park, NJ 07650
Tel: 201-429-2866

3556 159th St. #2nd Floor, Flushing, NY 11358
Tel: 718-939-6137

WORKFORCE DEVELOPMENT

125 West 30th St, #1107, New York, NY 10018
Tel: 929-300-8630, 929 341 8502

410 Broad Ave. #201, Palisades Park, NJ 07650
Tel: 201- 479-2866

MENTAL HEALTH CLINIC

42-16 162nd St, 2FL, Flushing, NY 11358
Tel: 718-366-9540

410 Broad Ave. #201, Palisades Park, NJ 07650
Tel: 201- 429-2866

IMMIGRATION & LEGAL SERVICES

410 Broad Ave. #201, Palisades Park, NJ 07650
Tel: 201- 446-5260

Many of our seniors are at high risk for Type 2 diabetes. For Medicare and Medicaid beneficiaries— especially immigrants—the healthcare system can feel impossible to navigate alone.

KCS, as a recognized organization to deliver the CDC Diabetes Prevention Program (DPP), we meet older adults where they are: in senior centers, churches, community rooms, and virtual spaces. One participant, a Medicare member with an A1C level of 6.0 or higher, after joining the program, receiving

personalized coaching in Korean, and being connected to nutrition resources, had her A1C drop dramatically—preventing disability and preserving independence.

Programs like ours reduce long-term Medicare spending, prevent amputations and disability, and keep older adults active in their communities.

Story of Clients to Access to Long-term Care Consultation, NYC Benefits and ACA Enrollment Long-term care guidance:

Mr. P has been living in a nursing home since last year after suffering a stroke that is related to diabetes. During this period, he lost vision in both eyes due to severe diabetic complications. Mr. P and his family believed that the care they were receiving in the nursing home was no longer sufficient, so the consumer decided to discharge themselves. However, after leaving the facility, their Medicaid coverage was terminated, leaving them without access to any services.

At this point, Mr. P contacted KCS (Korean Community Services) for assistance. While we were helping the client apply for expedited Medicaid, their condition worsened, and they were admitted to the hospital through the emergency room. After stabilization, he was transferred back into the Nursing home. Throughout this time, the client consistently expressed a strong desire to receive long-term care services at home rather than remain in a nursing home. They also wished to receive appropriate treatment through regular Medicaid rather than Medicaid limited to nursing home care.

To support the client's goal of returning home safely, our team requested and coordinated a NYIAP(NY Independent Assessor Program) Assessment 2 while the client was still in the nursing home. This assessment was critical for determining the level of long-term care services the client would need in the community and for ensuring that appropriate support could be put in place before discharge.

HEADQUARTERS (ADULT DAYCARE EDUCATION; HIP, IMMIGRATION & LEGAL SERVICES, PUBLIC HEALTH AND RESEARCH CENTER; WORKFORCE DEVELOPMENT)

203-05 32nd Ave, Bayside, NY 11361
Tel: 718-939-6137

OLDER ADULT CENTER

42-15 166th St, Flushing, NY 11358
Tel: 718-886-8265

37-06 111th St, Corona, NY 11368
Tel: 718-651-9220

633 W 115th St, New York, NY 10025
Tel: 718-886-8265, 347-923-0124

PUBLIC HEALTH AND RESEARCH CENTER (1)

315 5th Ave, #705, New York, NY 10016
Tel: 212-463-9685

2460 Lemoine Ave, #400F Fort Lee, NJ 07024
Tel: 201-364-8375

103-04 39th Ave, #103, Corona, NY 11368
Tel: 917-396-4149

PUBLIC HEALTH AND RESEARCH CENTER (2)

410 Broad Ave. #201, Palisades Park, NJ 07650
Tel: 201-429-2666

35St 159th St, #2nd Floor, Flushing, NY 11358
Tel: 718-939-6137

WORKFORCE DEVELOPMENT

325 West 38th St, #1107, New York, NY 10018
Tel: 929-300-8630, 929-341-8502

410 Broad Ave. #201, Palisades Park, NJ 07650
Tel: 201- 479-2666

MENTAL HEALTH CLINIC

42-16 162nd St, 2FL, Flushing, NY 11358
Tel: 718-366-9540

410 Broad Ave. #201, Palisades Park, NJ 07650
Tel: 201- 429-2666

IMMIGRATION & LEGAL SERVICES

410 Broad Ave. #201, Palisades Park, NJ 07650
Tel: 201- 446-7268

Additionally, we assisted the client with applications for Medicare and Social Security Disability benefits so that they could secure stable health coverage and the income support necessary to maintain their medical care. We also located a home care agency capable of meeting the client's complex needs and provided a direct referral, helping lay the groundwork for a safe transition from institutional care to community-based long-term services.

Navigation on NYC Services of DSS

Our clients often tell us, "I am grateful to KCS Korean services as I can speak in Korean."

Many have lived in New York for decades but have never applied for SNAP, housing application assistance, or Medicaid simply because language and paperwork feel overwhelming.

KCS culturally and linguistically competent navigators assist thousands of New Yorkers each year with:

- NYC benefits applications
- Affordable Care Act (ACA) enrollment
- Medicaid and Medicare guidance and consultation
- Long-term care options
- Chronic disease resources

One older adult with mobility challenges had gone without insurance for years without proper documentation. With our help, he enrolled in Medicaid for 65+, accessed preventive screening, and began therapies that allowed him to walk again without assistance.

Building Memory Health and Human Connection: Dementia Prevention in the Community

Dementia affects Asian American families at growing rates, yet stigma often keeps people silent. Many of our seniors fear that memory loss will lead to immediate nursing home placement, so they avoid seeking help. Our Community-Based Dementia Prevention Programs, including the new 'Brain Health Academy', are designed to change that. Through in-language classes on cognitive health, music and art therapy, mindfulness, nutrition, and movement, we give seniors tools to stay mentally strong while reducing fear and stigma.

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Tel: 718-939-6137

OLDER ADULT CENTER

42-15 166th St,
Flushing, NY 11358
Tel: 718-886-8203

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Corona, NY 11368
Tel: 718-651-9220

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New York, NY 10025
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347-923-0124

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07024
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Corona, NY 11368
Tel: 917-396-4149

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410 Broad Ave. #201,
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Tel: 201-429-2866

35Sb 159th St. #2nd Floor,
Flushing, NY 11358
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325 West 38th St.
#1107, New York, NY
10018
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929-341-8302

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Palisades Park, NJ 07650
Tel: 201- 429-2866

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42-16 162nd St. 2FL,
Flushing, NY 11358
Tel: 718-366-8540

410 Broad Ave. #201,
Palisades Park, NJ
07650
Tel: 201- 429-2866

IMMIGRATION & LEGAL SERVICES

410 Broad Ave. #201,
Palisades Park, NJ 07650
Tel: 201- 446-5268

One participant in her 80s, living alone—had been worrying about her forgetfulness and fear of dementia. She was so excited to hear about our new program on dementia prevention. We will soon kick off the first classes on December 13 and 20th. Many potential participants contact us to learn about preventive measures. Community-based dementia programming preserves independence, reduces caregiver burden, and keeps older adults emotionally and socially connected.

The older adults we serve want to remain in their homes, connected to their families, faith institutions, and cultural communities.

Thank you for your leadership and for uplifting the voices of vulnerable older adults nationwide. We are honored to share their stories.

HEADQUARTERS (ADULT DAYCARE EDUCATION) HR IMMIGRATION & LEGAL SERVICES PUBLIC HEALTH AND RESEARCH CENTER WORKFORCE DEVELOPMENT)

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Tel: 718-939-6137

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42-15 166th St,
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Tel: 718-886-8203

37-06 111th St,
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Tel: 718-651-9220

633 W 115th St
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Tel: 718-886-8203,
347-923-0124

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315 5th Ave #705,
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2460 Lemoine Ave,
#406P, Fort Lee, NJ
07024
Tel: 201-364-8375

103-04 59th Ave, #103,
Corona, NY 11368
Tel: 917-390-4149

PUBLIC HEALTH AND RESEARCH CENTER (2)

410 Broad Ave. #201,
Palisades Park, NJ 07650
Tel: 201-429-2866

3556 159th St. #2nd Floor,
Flushing, NY 11358
Tel: 718-939-6137

WORKFORCE DEVELOPMENT

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#1107, New York, NY
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929-341-8302

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07650
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KCS

Work Force Department – Helen Jang, Senior Director of WF

Hello, my name is Kim Kwang. I am 77 years old, and I currently work at a senior center through the SCSEP(Senior community services Employment Program) program.

The summer of 2025 in New York was, as always, fast-paced, cold, and unforgiving. As an immigrant, just getting through each day was not easy. My English is not perfect, I am older, and my work experience does not match the American system. I truly did not know where or how to begin again.

And then, SCSEP reached out its hand to me.

Through SCSEP, I travelled every morning to a small nonprofit organization where I was placed. With the income I earned, I was able to recharge my MetroCard, buy groceries, and—for the first time in a long while—feel that I was standing on my own two feet in New York City. More than the small paycheck, what meant the most was having a place where someone looked at me and said, “We need you.”

This program was not just job training for me.

It gave me back a sense of purpose—something I thought I had lost.

So when I heard in July that the program was being suddenly furloughed, my mind went completely blank.

“How am I going to pay this month’s rent?”

“Am I going back to being unemployed again?”

“Am I going to be alone… all over again?”

Life in New York as an immigrant often means there are no close family members to rely on, and very few support systems to fall back on. The moment SCSEP stopped, people like me hit a wall of harsh reality. Many participants around me began cutting medication, reducing meals, and some were afraid they wouldn’t be able to pay their electric bills.

In that moment of fear and uncertainty, the person who gave us hope again was Senator Kirsten Gillibrand.



She understood how essential this program is—how it supports the lives of immigrants, seniors, and low-income individuals. She spoke up on our behalf and sent a letter to the federal government explaining why SCSEP must continue.

Our voices are small.

Our English is limited.

And politics often feels far away from people like us.

But Senator Gillibrand carried our stories for us.

Because of her support, advocacy became possible, and in mid-October, the door finally reopened—SCSEP resumed. On the very first morning the program restarted, I cried quietly on the subway. I cried because someone had remembered us… someone had cared.

The support letter Senator Gillibrand sent was not just a document.

It was a hand that lifted us back up.

On behalf of the KCS WFD Department and all SCSEP participants, I want to express our deepest gratitude. This experience showed us—clearly and powerfully—how leadership and compassion can change real lives.

Thank you.

Truly… thank you.

We will never forget what you have done for us.

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IMMIGRATION & LEGAL SERVICES

410 Broad Ave. #201, Palisades Park, NJ 07650
Tel: 201-446-5264

My families story.

I am Roy Probeyahn a life long, Long Islander as is my family.

The first time my bride Arleen and I heard the word Autism was in late 1963, 62 years ago. High school sweethearts, we had been married just two years, and our eldest son Roy was but a year old. Yet, we would go on to learn that ultimately all three of our beloved sons—Roy, Mike, and Glenn had— Autism We later learned we are a Fragile X Syndrome family. Institutional care was the only care NYS had to offer then. We visited one, you have heard of it, Willowbrook. When we left, we made another vow to each other; our sons are going to live in their own home with us for the rest of their lives. We succeeded but could not have given them this community living opportunity without Medicaid Home and Community-Based Services (HCBS)!

We devoted our lives to advocating for our children and others with Intellectual and Developmental Disabilities. (I/DD). Our sons went to parent founded provider agency I/DD schools until IDEA was enacted in NYS in 1976. Under the Medicaid waiver we were the first family to receive residential services, for their sons who were living at home, with their Mom, Arleen and I, when Tom Maul was the Office for People with Developmental Disabilities (OPWDD) Commissioner.

My dear cherished bride of 50 years, passed away about 15 years ago. Roy tragically passed away 7 years ago after choking on a bakery donut he stuffed into his mouth, in the dining room of our home while a burnt-out under paid staff did not watch him, as he knew he was to do. And his youngest, brother Glenn, passed away 4 years ago in September when his heart gave out after several health complications stemming from a catastrophic fall in the bathroom due to staff error.

In January 2019, our in-home residential services were cancelled by the I/DD agency provider who had served them for 20 years with OPWDD

funding. It was their staff who was responsible for our son Roy jr's death.

I had to set up self-directed care with OPWDD to have Mike and Glenn continue to receive that part of their care. I became an immediate supervisor of a staff of 7.

It has been a constant struggle to recruit and retain staff because the pay is so low. Direct Support Professionals (DSPs) left to take other jobs. Two moved out of state because they could not afford to live on Long Island, while making minimum wage.

After my Arleen passed away, it took several years, but we received approval from OPWDD to convert our home for Mike & Glenn into a Group Home, (Individual Residential Alternative - IRA) and 3 other gentlemen. The house is converted completely to be certified. With Roy and Glenn's passing away, for 6 years both agencies I was working with, had been unable to hire DSPs for our IRA to be certified and opened. Due mainly, to the low salaries NYS rate setting allows, under HCBS funding

They have now withdrawn from the project with the continuing Workforce Crisis they will not be able to do it until NYS will provide sufficient Wage Enhancement to create and achieve Pay Equity with DSPs in NYS IRAs and Day Services doing the same work.

I am now 86 and Mike is 62. He does not speak, is legally blind with profound Autism and Intellectual Disabilities and physical disabilities. I can no longer care for him. I want Mike to become safe here because he is not safe now. For that to happen, NYS must invest in critical supports for people with I/DD. I am terrified to think what will happen if I die before him!

The care for our aging loved ones with I/DD living at home with aging parents, is a time bomb waiting to explode! Adequate funding must be provided for many hundreds of such families, untold numbers of them

by New York State with vital increased Medicaid Home and Community-Based Services (HCBS)! Stop the closure of IRAs by OPWDD, due to lack of staff inadequate wages, open new ones to accommodate these vulnerable people, our most vulnerable, who cannot care for themselves, before the caregiver parents die and they become homeless.

“The test of government is how it cares for those in the dawn of life, the children, those in the twilight of life, the aged, and those in the shadows of life, the poor, the sick, the disabled.” HHH

Thank you,

Roy Probeyahn

Mike’s Dad

Job Path, based in New York City and founded in 1978, supports hundreds of adults with autism and other developmental disabilities every year in the workplace, the community, and at home. With Job Path support, people can explore what they want out of life and chart their own journey.



For three decades, we've been honored to provide Home and Community-based services through our Supported Living program to one of the pioneers in the disability rights movement. Nina G. was one of the named plaintiffs in the historic Willowbrook Consent Judgement, signed in 1975, which led to the shuttering of the infamous institution, which was rife with abuse and neglect.



Willowbrook was finally closed after years of advocacy from people including Nina's mother, Diana McCourt, and an expose from Geraldo Rivera. Nina does not communicate verbally, has a profound intellectual disability, and - in her youth - had significant self-harming behavioral challenges. After several other residential settings, Nina came to Job Path more than 20 years ago, and has lived in community-based environments since then.



Now 64, Nina has her own room festooned with one of her favorite things - butterflies - in a spacious 3-bedroom apartment with two other Job Path participants and round-the-clock support from Job Path staff. Over the years, Nina has joined in at holiday parties and celebrations, taken classes in arts and music, enjoyed the outdoors, and travelling throughout the city, as well as the regular, everyday life of *community* - meals, laughter, games, friendship.



As one staff member puts it: "Nina knows much more than she lets on." These days she enjoys lounging in her recliner, listening to music, indulging in sweets, and she lights up when her favorite support worker comes into the room. Over the years, as Nina's interests and needs have changed, Job Path has been able to respond.

After a recent screening of a Willowbrook documentary Nina's mother recounted what it was like for her daughter to move to community-based care two decades ago.

"She looked in the door and was a little suspicious but she did a little hop and skip. That day almost all her behaviors changed and she didn't hurt herself any more ... I learned that the environment you have people in is going to nurture them, or kill them and Job Path is a nurturing place."

Job Path - 256 W. 38th Street, New York, NY 10018
jobpathnyc.org

Haley Walton, Broadalbin, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because it gives those who are less fortunate than myself the opportunity to be supported in their learning of how to live on their own to their best abilities.

Angele LePage, Massena, New York

Dear Members of the Special Committee on Aging,

In a world slashing Medicaid & many other life lines remember: behind these cuts are voices that are disregarded & ignored. Cutting Medicaid doesn't save money; it erases futures. My son Jared, is a young man with Down Syndrome. At the present time Jared is enjoying the routine of his daily programs. He attends activities that are essential to his esteem and personal development.

Every morning Jared is up at 6:00am and preparing for his day. After leaving the house he arrives at his programs where he finds a sense of purpose, where he is part of the 'crew'. He isn't in his bedroom fading into the background of life. Jared shows up. He has learned that he matters, makes a difference in the lives of others.

Should Medicaid funding be eliminated for Jared's programs, and services, he will sadly face many of the social & emotional side effects. Isolation, depression and hopelessness to name just a few. These are real issues that are as hard on the body as the most devastating physical illnesses.

Medicaid programs provide a purposeful life for Jared. He is happy, he loves the same things that you enjoy! He has great friends, he loves watching football with his father, he likes texting, laughing, joking and especially his daily 'work'!
Without the funding from Medicaid Jared will spend his days in his bedroom. Doing what? Well, I believe that question has clearly been answered here.

In closing I ask that you consider giving a voice to those who can't. Jared, as well as many others, deserve your undivided attention to this matter. They count on you to make the difference. They count on you to stand for them.

Dawn Tortora-Morici, Valley Stream, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because
I have two sons with developmental disabilities and their services improve their quality of life and integrate them in the community…

Nancy Tomlinson, Oswego, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because we all need to feel connected to our community.

Tyler Bridges, White Plains, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because as a person with a disability, finding a group close to me who can support me is dire.

Aaron Phinney, Centerport, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because
My son Cole would be lost without his group home at New Hope Community
He is 28 and requires 24 hour supervision
He has Angelman Syndrome
Without government funding I don't know what would happen to him
My wife and I are seniors and there is no way we could take care of him
Medicaid HCBS is essential
Please continue to fund this program
Thank You

Sherry Yates, Rochester, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because it is important to live up to their full potential .

Jude Asphar, Woodstock, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because it is something I have never achieved as I continue -- alone --to have to subsidize and accommoate my ASD house mate for 25 years never imagining his brilliance and undiagnosed lifelong ASD would mean he has no conscience and his over ambitious, grandiose work projects produce NO financial results, under my roof as daily, my 79 yrs of life disbelief that I continue to pay a huge life price for this man. Yes, we oldies for whom there was no diagnosis or recognition daily pay a heave price. That said, continue your crucial work for everyone you are aware of, who needs it -- while I wish I had some help to support this severe dissociation and denial that daily takes a toll on my life.

Laurie Clothier, Corinth, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because it makes life easier and more familiar.

Zachary Hilty, Olivebridge, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm 36 years old, I have a very active life with lots of friends and family who live nearby. I work, I do a lot of advocacy around disability related issues. I may able to do some gardening and have correct vegetables and have a wonderful dog I spend lots of time with. If I was forced into an institution my quality of life will go down the drain. I get much better quality of care with the help of my aides then the neglect I would have in a facility

---

Keith Gurgui, Lake Katrine, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm paralyzed and require 24 hour Personal Care to live at home.

Robert Wallen, Staten Island, New York

Dear Members of the Special Committee on Aging,

HCBS programs allow my daughter to get out of the house on a daily basis. She looks forward

going to her Day Hab programs. Kerry's day programs provide activities that I could NOT possible provide for her. She also will never miss Friday's This is the day she gets to deliver meals via Meals on Wheels to the home bound. Kerry gets great satisfaction by helping others. If Kerry did not have these programs she would sit home on the couch and watch You Tube all day. This would not be good for her, her mother or me. She gets very frustrated when she is not able to go out into the community!!!

Michael Bott, Queens, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because my son is disabled and needs help in everything and everyday living

---

Anthony Beck, Silver Creek, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because
My son now 43 is completely other abled in the early years, surgeries and treatments kept us busy
The school years came at a time when inclusion was the thing, he and we benefited from his education which was focused on what he could do.
Then as his age increased our ability to care for him diminished, and he agreed to go into a group home
Initially he was taken into the community on a much more regular basis where he enjoyed concerts and other things
Dayhabs do their best to follow up but no longer provide those outside attractions
So at the end of the day he ends up in his room door closed (as his building mate is quite loud) recycling books tearing them apart page by page
So much effort was placed on preparing him for society only to have it abandoned after high school graduation He could hold a job but needs an attendant for toileting

---

Linda Millemaci, Buffalo, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because we all need to help build up communities

---

Ned Durkovic, Flushing, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because it benefits everyone.

Nancy Crom, Albany, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I was just diagnosed with spinal stenosis, and have trouble walking and getting around. I may well be signing up for the home based community services soon and I will need them! Don't touch them!!!!!!!!!!!!!!!!!

Darcy Janowski, Castleton-on-hudson, New York

Dear Members of the Special Committee on Aging,

Community living matters to my family. My nonverbal severely autistic son went psychotic attacking all of us this past winter. This was due to no programming available after aging out of school. He is now living in a residence 2 hours from us and has a dayhab program. It would be better if he was closer and he could have stayed with us. There aren't enough services for all that need them. My daughter is also autistic and in a dayhab program living home. These programs allow them to connect with other people in their community. We would be lost and struggling terribly without these programs and services.

Jean-Paul Stiller, New York, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because without community, children can't learn, adults can't join causes, and all causes for justice would be lost.

Mary Becker, Troy, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a daughter with developmental delays and I am 68 yrs old!!!

Greene Rita, Oneonta, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because
My brother lives in a ARC home he couldn't live on his own he needs the assisted living the access to his medicines and ramps and tub shower wheelchairs can go in

---

Kevin Buckley, Liverpool, New York

Community living matters to me because I am a Father of a 38 year old daughter with Down Syndrome. She is the oldest of my two children. She lives a very independent and meaningful life that I could never have imagined when she was born. Meghan makes the world a better place one day at a time and one person at a time. She does it by just being herself. Everybody that knows her will tell you how she has taught them so much. They have learned that the expectations are endless if these individuals are treated with respect and dignity. In my local community I am known as Meghan Buckley's Dad and very proud of that. My wife and I have been champions for the programs such as HCBS and many others because we know our daughter would not be where she is now without these services. I tell people Meghan is my "Peace Cloud" because she brings happiness and joy to everybody she meets or just people that happen to cross her path (i.e. airport, malls). She is living the best life I could have ever imagined. Then add onto someday my wife and I will not be around and her Sister lives on the other side of the country. We obviously will do all we can to leave her in a good situation but these support programs will always be required to maintain her quality of life. I would be honored to share our experiences to anybody that wants more details. I would fly to DC on my own dime to speak to anybody that wants to listen.
Sincerely,
Meghan Buckley's Dad Kevin

Naome Adam

Dear Committee Members,

I am an older person who happened to have developmental disabilities. In the past year, I have gotten help from the office of Aging and office of OPWDD. I also happen to be on the NY STATE council on Developmental disabilities.

I currently get Medicaid waiver services from OPWDD. I get help with things like learning

I get help with skills in my house, the community and at my job.

I also get help help with nursing and personal care and house keeping.

one of the things that many of my friends and i deal with is yes, we have self direction funs but its not in consideration of full time 24 hours of help with com hab.?

MANY OF MY LOCAL FRIENDS THE CASE MANGER SAYS IF YOUR FAMILY MEMBERS NEEDS MORE THAN A GROUP HOME, THE ANSWER IS NURSING HOMR/ BUT IT HAS NEVER THE ANSWER, AND WORSE ONCE IN NURSING HOME, THE PERSON WITH DISABILITY LOOSE ALL SERVICES FROM OPWDD. THEY LOOSE EVEVN CASE MAGEMENT SERVES. NO ONE IS HELPING THE FAMILIES,

ANOTHER TERRIBLE ISSUE, IF SOMEONE IS HOMESLEES AND HAS DISABILITY, AND OLDER THEY ARE SENT TO MOTEL WHERE THERE IS KNOW SEX OFFENDERS, THIS IS GROSS. NEGLECT ON PEOPLE PART. I KNOW THIS EXIST, SINCE I HAD TO ADVOCTE TO GET PEOPLE OUT,.

Here is what i am missing.

Affordable one level place among seniors, not a group home for people with disabilities.

My town house has grab bars now and walk in shower, where can i find another places with those feature?.

I can not afford senior retirement community>`

If I was in a senior living place, i could have built in neighbors and , companionship, and assistance while i wait for help. I would have built in staff at office desk.

Not every person with a disability needs a group home, there has to be alternatives.

One problems is lack of staffing, and I want to be among others not necessarily all with disabilities.

I want an accessible place especially to take a shower that is affordable and not be on a 5 year waiting list..

Laura Kearins, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because we are people too!

Jb Pelkey, Plattsburgh, New York

Dear Congress Reps,

One of the things about living independently and having special needs is that i am alone. I do not have anyone assisting me. I could not pay for such important services without help whether it is the Arc or Bhsn. I have been diagnosed as having aspergers. I have physical disabilities. Medicaid and Medicare pick up the slack. I just want to ask that you please support those of us who are needy. Thanks for your time.

Sincerely,
Jb Pelkey

James Russell, Franklin Square, New York

Dear Members of the Special Committee on Aging,

I am the father of a 17 year old girl with autism and lgs ! My daughter has been badly treated by new york state , Franklin square schools , sewanhaka schools , Brookville school for autism ! Gov Hockul and gov Cuomo repeadly cut the budget for these children , to fund illegal aliens and other assorted criminals ! Long island school districts are top heavy with overpaid administrators who do nothing but warehouse these children ! Opwd the state agency in charge of these kids is still on covid lockdown, doesn't matter they do nothing anyway ! The agency's collecting money to help these kids are just money hungry thieves ! Nys needs to be investigated from the top down by Pam bondi and the fbi !

Judith Jarer, Nyack, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because People with disabilities and older adults deserve to live with independence, dignity, and connection to their communities

---

Daniel Mittermeyer, Greece, New York

Dear Members of the Special Committee on Aging,

Community living matters to me ,-because my fiancé ,Erika ,-has worked in that field of caregiving for many many years… and I grew up with parents who volunteered each year for the Special Olympics and we also had a couple of my own family members,- who were folks with disabilities… and the simple fact ,-that unalienable rights in our democratic experiment,- now

under complete destructive attack by tyrant- traitor -toddler -Trump …!!! and his criminal cabinet of project 2025 far -right- religious- FASCIST lunatics …!!! has shown that they have no compassion or care for these matters whatsoever…!!!

Elizabeth Barber, Penfield, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I feel more connected to the place or people in the community.
We already warehouse people in Nursing homes and don't take them out to a restaurant or a movie or even a drive around to look at the Christmas lights. When you look at 4 walls day in day out, you feel like a number, a person just waiting to die.
People have to be connected to live and grow or simply to regenerate feelings of being connected.

Len Carella, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a son with disabilities. He receives services such as speech and psychotherapy weekly from AHRC in the Bronx. He has been attending this program since he was 18, he's now 47. He lives at home and has transportation provided by the program. AHRC has helped him communicate with others and learn to be a responsible adult.

Krishna Dhru, Mount Kisco, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because without that we are taking away basic rights

---

Derek Curtis, Liverpool, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I am capable of living independently, but I need assistance with many of my daily living skills.
I do not drive so I need transportation to get groceries, meet up with friends and to get to volunteer opportunities. I love having my own place but I cannot afford my apartment and my

utilities on my own. I want to be a productive member of society and with my DSP's help I can achieve my life goals

---

Barbara Fitzsimmons, Corning, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because as an Occupational Therapist I have treated children who needed the Medicaid Waiver to pay for equipment such as Wheelchairs, and Communication devices. I also feel that the community programs that support adults with different abilities are critical to their well being and keep them active in the community and out of residential care.
To remove these services would mean families would bear out of pocket cost for necessary medical equipment and differently abled adults would have fewer choices for community programming.

Polly Walker, Queens, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because. Thank you

Carol Pratt, Buffalo, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities should have all the same opportunities as everyone else

---

Rita Aziz, Great Neck, New York

Dear Members of the Special Committee on Aging,

Community living matters because special needs people need assistance need supervision and they need to feel good about themselves. It really matters and changes lives for the better.

Veronica Barajas, Albion, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because we care for our family and neighbors.

Meredith Kent-Berman, New York, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I want to be part of the mainstream!

Genevieve Thacher, Binghamton, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because individuals with disabilities do so much to enrich their communities. They are dedicated employees, community members, friends, and family. They rely on community programs to live the types of lives that those without disabilities sometimes take for granted. It is our responsibility as members of our community to ensure that these individuals get the same opportunities to live meaningful lives as we do.

Beverly Bullock, New York, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because every member of the community is important.

Joseph DeFeo, Yonkers, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because think of the children

Klaus Lessnau, New York, New York

Dear Members of the Special Committee on Aging,

Medicaid remains important.

Tyrone Lee, Ridgewood, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because we must protect what's ours

---

Jeremy Young, Queens, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because it's our community! Who else will take care of it?!

Christina Raptis, Commack, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I am raising a special needs child.

Terry Brown, Hoosick, Falls, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a 37 year old daughter who deserves to live her best life. She requires day hab services which enhances her social, mental and physical skills. She is an adult and deserves to live in her home with 24 hour supervision to be able to become as independent as possible. We as parents should not out live our children and therefore I feel very strongly that I set up a good support system for her now. These programs are so important to the special needs community. Please continue to support their services.

Deborah Lombardi-Aiello, Wading River, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because my Autistic son receives HCBS. These services allow him to remain integrated into our community, providing community habilitation which teaches him how to live independently. It also allows him the opportunity to take community classes and learn alongside his peers, strengthening relationships and learning real world skills.

If this were to be taken away, he would be more isolated and less independent. He would not contribute to society like his typical peers. His lack of independence would lead to tragic outcomes when his family are no longer around to care for him.

Please preserve this critical funding for Medicaid HCBS.

Joan Conca, White Plans, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps everyone to live free, healthy and happy.

Elizabeth Schwartz, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities and older adults deserve to live with independence, dignity, and connection to their communities.

Laurie Cleveland, Saint Regis Falls, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I am 71 years old. There are very few resources up here for people needing services and the poverty level is so low that people like me fall between the cracks.
I need to get into a pool, but all of the pools except for a tiny infinity pool at a hospital aren't accessible for people with mobility issues and they are not heated properly for older people like myself with joint problems.
There is another pool over an hour away and while it is ARC, it is small and if I need to do laps along with exercise, only half is deep enough for me to do that. So, places like Clarkson or SUNY Potsdam or several other places need to get with the program and heat these pools up and instead of some of these crazy plastic contraptions, they need to have stairs with handrails that they can pull up for swim team and put them down at other times. This was done at the Y in Taunton, MA and the Agricultural College in Randolph, VT. It can be done. The other problem is proximity to the regular gym facilities. At Clarkson, it's a bit of a hike. I understand fully well the difference from being young and my mum insisting that I get out of freezing cold water, which didn't bother me at all. I was very active, but then juries occur, life happens and this becomes tough.
I bought a house with a pond and I was lied to about everything. It was very polluted from the neighbors horses using it. I ended up getting pretty sick from E. Coli and there were children using it. So I researched and found a product I could get the pond cleaned up so that I wouldn't have to report them. Once in the water, I swim like I was young as long as it isn't freezing out

and this pond was so clean, it was coming back to life. Even had a couple of brook trout in it. I also told them that if they planned on letting the kids from their summer horse program come over, give us a ring and one of us would assume lifeguard duties. I already have saved several kids from drowning at the St. Regis river public beach. I know that people don't get their kids to Red Cross swimming lessons and either they can't swim or they don't do it very well. Understatement.

Then there is the problem of getting a decent dentist. I had to wait to get another appointment. I am a cardiac, pulmonary and kidney patient so having a bad tooth or needing deep cleaning and now another tooth is splitting and loosening. Anything like this causes problems with sinuses and then the infection can go to lungs or heart. This is very common and many people end up with no teeth and if they are lucky. They get poorly fitting dentures which can cause all sorts of problems. I don't know about you, but I don't particularly want a mechanical soft diet. They are inedible, overcooked and bland. Even the dog will walk away.

I worked in almost every discipline as an RN and ended up as an RN home health case manager. It was demanding, I could use my talents and was a very strong advocate for my patients. I made a difference in their lives. I have watched as people got denied services that any fool could see that they needed and the abuses by the systems put into place to protect them failed miserably. In one state, I had several people that needed either to be placed or needed better housing. One was actually condemned by the Board of Health only to be told that the elderly person could stay. She was being manipulated financially by another relative, while the ones who found her in this state were the ones that were trying to help her. The problem was a !0 y.o. dog that was using her and every place as its toilet. No running water except for a rusted pipe in the kitchen, mouse and rat nests everywhere. They had repaired the furnace that had died sometime during the winter. She was a hoarder. They found dead cats upstairs, the ceiling was leaking. Antique wallpaper with green which they used arsenic to make and the final problem? Asbestos. The air quality was so bad in there that I had to finish the interview outside. We had tried to get her the help that she needed onto to be told by the state it was her decision and it was clear that she couldn't take care of herself and while I loved animals, and I know how much she loved that dog, whatever his issue, he couldn't be housebroken. She certainly couldn't take him for walks and normal dog behavior is they don't use the person as their personal potty. Then there was a man who had a whole in his floor of his trailer and plumbing problems. Couldn't take a shower or get washed up in tye bathroom. Actually, he needed a new trailer. I nearly fell through that floor when using the kitchen sink to wash my hands. It was that rotted. Then there was a couple who were denied because the social worker didn't use whole dollar amounts. They were $5 over the limit and services denied. I'm sorry, but $5? I had run-ins with the VAMC on a regular basis. I was really good at my job. I did it well. Really well. I just shook my head at their inability to understand the serious concerns. It's everywhere. Just before MA decided to carve up MA into different sections every provider save one exited my area. That one had 2000 patients. I had to put it in writing a request to keep my primary of 20 ,years who was in a town not covered. Some hospitals refused patients to be cared for because they didn't have the right insurance.

When big corporations buy up all of the hospitals and VNAs in a particular area and protocols supersede commonsense and individual care plans, the hospitals take off older controlled substances and Big Pharm and insurance companies are saying what a person can and cannot do, it's a major problem. I have literally been killed twice, nearly 5 other times and as an RN, retired or not, I know what is right and what is wrong. I had a massive lower GI bleed caused by over heperization. Hospital policy said heoarin in belly. I was already on plavix and ASA, 81mg. I wasn't bedbound at that point, but I was once that blood came pouring out. I had protested because a heparin solution for IV's and the old SASH metged is used and i have lousy venoys access. They didn't have that proticol anymore because of heparinized PICC lines. Well, a short line or a midline or a central line isn't a heparibized PICC line. The others need that. Then I required 4 blood transfusions. All were done incorrectly. They were supposed to have a filtered IV drip in case of clits. Two RN's have to hang the blood together to make sure that it is the correct blood for the patient. Transfusion reactions are very serious.

At one hospital stay, this clearly mentally challenged patient was in the hallway clearly upset. I went out and spoke to him. He settled down. All he needed was that. Another hospitalization, I was seriously abused and from the sound of things it was rampantbon that floor. There are laws regarding the prescription of anti-psychotics. A damned PA cannot write the order. It has to be a board certified psychiatrist in good standing in the state. Mental status checks have to be performed. Now we get to people with pain. I prefer and want somebody who will do everything as far as regular care and that. More habds in the pot, more likely something will happen. I have a leaky TAVR. No real clinician will order 5-6 weeks of PT just to get it. This system did to my PCP what was done to me. I was just supposed to meet that new clinician. I didn't think much of her. She may have read my chart, but no questions and she decided or was forced to tow the new policy. Pain clinic. So, I am out of a PCP. Instead of letting my PCP stay put until she retired at the end of the year, they made her a float. So, I am out of part of my pain regimen. I am faced with a choice go to this person who is on the board of directors on both hospital systems, not likely, or go without. Some days possible to get days not. So I am forced to improvise. The OTC isn't good for my kidneys and ine i have replaced with herbal the last, I still have plenty of. I am not an addictive personality. My PCP only prescribed a certain amount of pulls a month and she actually changed the script. I do better with those closer to the plant source, not the new stuff. If its not on the formulary, and my pain revs up, I am told to suck it up buttercup. This isn't good patient care.

Anybody who has been diagnosed with a mental health diagnosis is automatically treated differently and finally vaccines. Kids are over vaccinated. I had to get a Td shot ss the company wanted another one. I am allergic to formaldehyde. My arm blew up like a balloon. When I asked for manufacturer, lot number, expiration date and looked it up. It had formaldehyde in it. That vaccine could have killed me! Nobody bothers to check meds anymore. People aren't protocols. Students cannot get certain skills like physical assessments on AI generated programs. I ask questions to find out what is going on. These change based on my understanding of the person. I can ask a question 10 different ways. I don't understand your question because it hasn't

been part of the program.
People deserve to get quality care. There are a lot of times I have to cancel an appointment, no transportation. Or if I need meds, and I don't have money for co-pays I can't get it. It's not about compliance although a person that I recently helped fell into that category, it's related to money or lack thereof.

Loraine Percoco, Islip Terrace, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because of my 28 year old son. He is autistic, and lives in a group home. I am getting older, and I worry about his future. I can only hope that people with IDD, will continue to receive the assistance they need to be participating in community life. They deserve to have meaningful and productive lives. Thank you.

Deborah Kair, Hartsdale, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because everyone needs to be part o a community (nit just a family). Without assistance the member of my family would not be able to participate and feel like she is able to help others too. The member of my family would be at home sitting in a chair. With help she is able to be a happy person who is able to feel the value of her life.

Anita Smith, Newark, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because people with intellectual disabilities deserve to live independent and having services through Medicaid teach them the skills they need to be independent.

Alec Thorp, Yorktown Heights, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities did T ask for their disabilities. Therefore, they have every right to get the same benefits and accommodations that any one else deserves to get just as well.

Daniel Fuller, Jamestown, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm disabled so to are my children. We depend upon services that are community based and understanding of our needs. We fear changing access or restrictions to it. Will make life that is already difficult, even more so. Please consider humans like us who have needs, hopes, dreams and aspirations in your heart and soul when you approach this matter.

Jennifer Divalentino, Harrison, New York

Dear Members of the Special Committee on Aging,

My young adult son has an intellectual disability and autism. He is 24 and is living a fulfilling life due to the support he receives from Medicaid HBCS. Philip has received job training in the community, job coaching in the community, participates in the local YMCA, local riding programs, recreation programs and a day program. He would likely be doing none of these things if it weren't for Medicaid HBCS. He would be sitting in the house alone. My husband and I both work full time. His siblings are all either in college or working and living on their own, Philip would be sitting in the house staring at the walls. That would dissolve into depression and accompanying poor behavioral control. We've been there before and we don't want to go back to those days in and out of the hospitals.
Now he has a full life. He has friends, a community, a social life, and he is working towards a work life. He has commitments that get him up and out most days of the week. His comhab worker brings him into the community daily and he has built relationships with the neighborhood shop owners and local people. Philip is happy and contributing to society. I really don't know where we would be without his services. Philip is funny, loving, and kind, and he deserves to have days that are fulfilling and engaged with the community. This weekend, he will go to see a local theater with a recreation group That's adulting! He has all of this because of Medicaid HBCS.

Therbie Galliotte, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because as someone who works people with special needs and disabilities, I see firsthand, the importance of independent living and having connections to their communities.

Patricia Altro, Baldwinsville, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because as a senior I have lived with a disability since I was six months old. I have counted on have have received help and love from the many communities I have lived in all my life, making my life more rich

---

Ryan Ford, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because one day I want to tell my story about how I live in my own apartment and receiving community habilitation

---

Alicia Johnson, Buffalo, New York

Community living matters to me because To Whom It May Concern,

As an in-home childcare provider and community caregiver in the City of Buffalo, programs like Medicaid Home and Community-Based Services (HCBS) have a direct and meaningful impact on both my life and the children and families I serve. HCBS supports allow individuals children, adults, and seniors to receive essential care within their own homes and communities rather than in institutions. For families I work with, this means their loved ones can maintain stability, comfort, and dignity while still receiving the supports they need to thrive.

These services also affect me personally as a provider. Many of the children in my care come from families facing medical, developmental, emotional, or financial challenges. HCBS often fills the gap by ensuring families have access to medical equipment, behavioral supports, therapies, and home-based assistance that I alone cannot provide. When families receive these supports, it strengthens their ability to maintain consistent childcare, employment, and overall household stability. It allows me, as a provider, to deliver safe, quality, and individualized care without being overwhelmed by unmet needs that fall outside of a daycare's role.

Kelli Baker, Canandaigua, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a 12-year-old grandson who is medically fragile,

special needs. Without Medicaid resources, we would not be able to keep him in our home. The medical supplies, medications, people who support him in all aspects, he would fail and we would as well. Zeke has a very rare form of epilepsy which is drug resistant. He's had thousands of seizures, numerous hospital stays, ambulance rides, currently takes seven different anti seizure medications. His seizures are still not controlled. He has a VNS system in place, feeding tube, medical Port as he gets phlebitis often. My daughter, his mother and his little brother Henry live with us. After she and Zeke's father divorced, she was struggling trying to take care of both boys with all of Zeke's medical needs on her own. Medicaid is the only way this works. He needs to be home and surrounded by people in his community/school who understand his health risks, and his learning disabilities. We are so grateful and fortunate for all the benefits he receives. With no end to his many medical difficulties in sight, it's the only way we see a future for him. As he ages out of school, the programs and assistance that will help our family and Zeke survive will be beneficial.

Melissa Hiam, Buffalo, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I have been working in this field for 14 years, alongside people with developmental disabilities who feel pride in living in a home of their own. Our agency supports the person with choice of where they want to live. Having the independence and autonomy to live your life the way you want to is important and many people without a disability take it for granted. Without the support from the funding for HCBS Medicaid waiver programs, many of the people we support would be homeless, hungry, and in unsafe situations. Many have no family that will help when times get tough. Fund these programs! People with DD deserve to have opportunities to grow, thrive and feel pride in their homes.

Kim Delplato, Caledonia, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I have 3 disabled young children and when they are grown having a community that serves their unique needs is a must. They need support emotionally, physically and mentally from a community that understands them. As well as a social community that they can find like minded people in and enjoy activities with.

Claudia Coen, Geneva, New York

Dear Members of the Special Committee on Aging,

Community living matters to me. I have an adult son with disabilities and am very active in the community of people with disabilities, with the right supports they are valuable members of their communities making meaningful contributions. The community is also important in their lives. My son has a barber, a pizza guy, a kung fu master, a nail salon - he routinely visits these businesses. They know him and he supports them.

Thomas Pintagro, Jamestown, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because we have many in our community who work and receive Medicaid. Losing these programs would be devastating.

Anne Tulowitzki, Buffalo, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I support individuals with disabilities to find jobs. This allows for more independence in their lives!

Marjorie Pattison, Farmington, New York

Community
living matters to me because I have worked all my life and had a husband that went on hospice for a couple of months. Time off then I had to strokes and can not work any longer. I receive $1041. Month.
There are a lot of people out there that have disabilities that can't work that need help with SSI

Danielle Rector, Gloversville, New York

Dear Members of the Special Committee on Aging,

i want my food stamps

Linda Jakubik, Perry, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because every citizen deserves equal treatment and health care.

Veronica Dona, Gloversville, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I have worked in this field for over 30 years and have the impact people with disabilities have in their communities. Promoting independence and making connections is important for all people to grow.

Annie Brinich, Brooklyn, New York

Dear Members of the Special Committee on Aging,

Medicaid Home and Community-Based Services (HCBS) strengthen entire neighborhoods, including my own, because they let children with medical, developmental, or behavioral needs stay safely at home, remain engaged in school and community activities, and reduce the strain on families who might otherwise face crises or institutional placement. When families receive supports like respite, home nursing, behavioral services, and care coordination, parents are better able to work, siblings are more stable, and households remain economically and emotionally resilient. That stability ripples outward: schools experience fewer disruptions, local health systems face less emergency use, community organizations can collaborate more effectively, and neighbors benefit from a more inclusive, connected environment. In other words, HCBS doesn't only help the families receiving services—it helps the whole neighborhood function with greater safety, cohesion, and opportunity. I love my neighborhood, and I want it to be resilient and functional. HCBS does that. If you're thinking of gutting these services you better have a freakin' awesome replacement lined up.

Judith Miller, Catskill, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because my dear sister has been living in a group home since just before my parents died. They spent their long lives advocating for the community and now as siblings, so are we. Our sister was born with a genetic disorder that rendered her severely impaired from about the age 12. I recall her earlier, more neurotypical days with a bittersweet mixture of nostalgia and sadness. Ever since she was in her 20s, our sister has lived in a group home sponsored by Aspire of Western New York. She is nearing 79 years old. We are aging too but we remain dedicated to her care inasmuch as we are physically and financially able to be. Without Medicaid and Aspire we would be lost. Please affirm and support those among us who are in such great need of government assistance. Be truly ProLife for the living.

Katie Bilow, Plattsburgh, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because everyone deserves to be able to live as independently as possible.

Len Carella, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because my son is disabled and I need to know that he will be able to continue living with help in a safe environment.

Elyse Montalvo, Medford, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a niece who is in her 40's who is living with Cerebral Palsy. Although she is high functioning she is not able to do certain things on her own. She can be easily taken advantage of. The programs that are currently available she needs in order to be part of the community and at the same time have people who can support and advocate for her where she cannot. I also work as a DSP in a residential program. If it weren't for the funds received from Medicaid the ladies I support would probably be home bound most of the time. But with our help they go out nearly every day and have lives outside of their home. If I weren't able to work in this field and help support people with disabilities it would impact me emotionally because these ladies have become my extended family. Their joy is my joy. Helping out a smile on their face will put a smile on my face. To me there is no greater joy than to help a person achieve their happiness. Without the help of Medicaid it wouldn't be possible.

Mary Gembecki, Pleasantville, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I do not want to be in a home. Just my home

---

Camara Foster, Mt. Vernon, New York

Dear Members of the Special Committee on Aging,

Community living matters because it reminds us that we are not alone—we grow, heal, and thrive when we have people around us who care. It also creates a sense of belonging and support that strengthens everyone involved.

Letisia Comstock-Allcorn, Oneida, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because it's my right to be able to live like everyone else! There is a difference between disabled and handicapped, for me living in a group home made me handicap. I couldn't live the life of my choice but now living in the community I'm not handicapped I am, thriving with a disability. Community living is the difference between simply living and thriving!

Shaeril McBrown, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because i want to help people with disabilities

---

Michael Muscaro, Purdys, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because as a Direct Service Provider the individuals that we serve directly benefit from the funding provided by HCBS. In fact the services provided by the funds would cease to exist. Thousands of Direct Service Providers rely on HCBS funds to provide services to a severely underserved population of Americans.

Elizabeth Rowntree, Delmar, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I see the positive impact on people's lives. In our community people with disabilities provide volunteering and support to the community and without funding these supports would not be possible.

Christina Scott, Niagara Falls, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps everyone, especially those who are in need.

Thyais Brown-Newball, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. Programs like Medicaid home and community-based services (HCBS) help make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.

Anthony Chobot, Queens, New York

Dear Members of the Special Committee on Aging,

I support disabilities

Meredith Kent-Berman, New York, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because I want to be part of the mainstream.

Esther Fischer, Brooklyn, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because
I have an adult brother with special needs.

I work at an agency that serves adults with special needs. We are not allotted enough funding to better serve our aging population.
Our population gets excellent care we need more funding for wheelchair accessible facilities for our aging population.

Gordon Wood, Malone, New York

Dear Members of the Special Committee on Aging,

Community living matters to me because



1 Van Tromp Street, Albany, NY 12207
Phone: (607) 329-0507
Website: www.alliance-nys.org
Email: tallen@alliance-nys.org

December 2, 2025

The Hon. Rick Scott
Chairman
Senate Special Committee on Aging
110 Hart Senate Office Building
Washington, DC 20510

The Hon. Kirsten E. Gillibrand
Ranking Member
Senate Special Committee on Aging
110 Hart Senate Office Building
Washington, DC 20510

RE: Statement for the Record – Senate Special Committee on Aging Hearing: "Aging in Place: The Impact of Community during the Holidays"

Dear Chairman Scott and Ranking Member Gillibrand:

On behalf of The Alliance of Traumatic Brain Injury (TBI) and Nursing Home Transition and Diversion (NHTD) Waiver Providers of New York ("The Alliance"), thank you for the opportunity to submit this statement for the record for the Senate Special Committee on Aging's hearing on the importance of community living for older adults and people with disabilities.

The Alliance represents providers delivering specialized home and community-based services (HCBS) under New York's Medicaid TBI and NHTD 1915(c) Medicaid waiver programs, which help individuals who require nursing home-level care live independently at home. Serving over 13,000 New Yorkers and employing thousands of professionals and home health aides, these programs save federal and state dollars while improving health outcomes, independence, and quality of life.

As the Committee continues its work to strengthen community living for older adults and people with disabilities, we urge you to consider the challenges facing Americans across all states like the vulnerable populations of New Yorkers who rely on the TBI and NHTD waiver programs. These waivers are lifelines for individuals with traumatic brain injuries and cognitive or physical disabilities, allowing them to

remain in their homes rather than in costly institutional settings. Yet, these programs face mounting threats that could undermine access to care.

These challenges include:

Access Issues from Federal Medicaid Financing Reform. Medicaid reforms included in Public Law No. 119-21 will have real consequences for the people we serve. These changes will tighten state Medicaid budgets, and programs like the 1915(c) waivers, which make community living possible, are often the first to feel the impact. When funding shrinks, providers are left with impossible choices: reduce services or close their doors. Added administrative hurdles, like frequent eligibility checks and retroactive coverage rules, create gaps in care that leave vulnerable individuals waiting for help they desperately need. Protecting these waivers is essential to preserving community living options for thousands of vulnerable individuals.

Capacity Issues from Conflict of Interest Implementation. The federal Conflict of Interest (COI) rule adds another layer of complexity. While designed to protect individuals, it has created serious barriers to continuity of care. Under CMS's HCBS Final Rule, providers delivering services under 1915(c) waivers cannot both deliver services and develop person-centered plans. In practice, across New York State this has led to provider shortages and delays, especially for waiver populations like TBI and NHTD. Conflicting definitions of COI across federal statutes only make the problem worse, causing unnecessary hospital stays and even nursing home placements. The human impact is real: one participant with complex medical needs waited months for basic supports like meal preparation and appointment coordination, and in another heartbreaking case, an individual died while waiting for placement on the TBI waiver. These stories show why federal leadership is urgently needed to align COI rules and provide a regulatory/legislative fix to protect access to care.

Lastly, the Alliance is increasingly concerned about the proposed enrollment cap on the NHTD waiver, which would limit participation to 9,400 individuals for three years once approved by CMS. While intended to manage costs, this cap would limit access to services. For providers, it means turning away individuals who could safely remain in their homes, forcing them into nursing facilities at greater expense to Medicaid and with far less independence.

The Alliance would be glad to serve as a resource for you and your staff in your work on the Senate Special Committee on Aging. We would welcome the chance to meet in the coming weeks to discuss our initiatives and how we can support your priorities.

Thank you for your attention to these issues and for your commitment to helping older adults and people with disabilities live with dignity in their communities.

Best,

John McCooey
Chairman
The Alliance

Traci Allen
Executive Director
The Alliance

PACE is an Innovative HCBS Model of Care in New York

The Program of All-Inclusive Care for the Elderly (PACE) is a federally authorized home and community-based (HCBS) model of care that enables individuals age 55 and over needing a nursing home level of care to live at home or as independently as possible. PACE programs coordinate and provide all needed preventive, primary, acute and long-term care services so older individuals can continue living in the community.

Through PACE, today's fragmented health care financing and delivery systems come together to serve the unique needs of each individual in a way that makes sense to frail elderly individuals, their informal caregivers, health care providers and policy-makers. PACE integrates and coordinates all medical care and long-term care services and supports for participants across all settings, including prescription medications, transportation and meals.

The following are three stories from New York-based participants around the difference their PACE program has made in helping them and their caregivers thrive while aging in their communities.

Connie – A Caregivers' Gift of Gratitude



Connie Rock arrives at the PACE day center with a bag of games and books, eager to leave them for participants to enjoy.

"These brought such comfort and joy to my husband as his Alzheimer's Disease progressed. Now that he has passed, I hope these can help someone else."

Ken, Connie's husband of 59 years, first showed signs of Alzheimer's in 2010. "He would forget names and ask the same questions over and over again. When we received the diagnosis of Alzheimer's disease, those subtle changes we noticed began to make sense."

Ken could remain living at home with Connie, but it came with some unique challenges.

“As the Alzheimer’s progressed, things became more difficult. Ken needed someone to be with him at all times to ensure he was safe. For example, I couldn’t even take a 5-minute shower because he would wander or try to eat something he shouldn’t. It was then I knew I needed help.”

In 2022, Connie called PACE CNY in Syracuse, New York after a relative suggested PACE services might be able to help. As a participant, Ken attended the PACE day center five days a week, leaving on a bus in the morning and arriving home in the afternoon.

“Ken would be excited to go,” Connie says. “He enjoyed his time at the day center, and I appreciated the break from caregiving so I could run errands, go to doctor’s appointments, and catch up with friends. Ken being enrolled in PACE was good for us both.”

Connie is thankful for PACE, who brought him joy during a difficult time. “Ken and I were big fans of Halloween, and I remember this past October how happy he was to wear a costume and celebrate with his friends at the day center. When he came home that afternoon, he showed me the mask they had given him to add to his cowboy costume, which made us both laugh. He made some good memories here, and I am thankful for the support we both received from PACE.”

Ben - Got Moving with PACE



“Check this out! Not many people have a walker like this, and I think I may be starting a trend—everyone wants one now!”

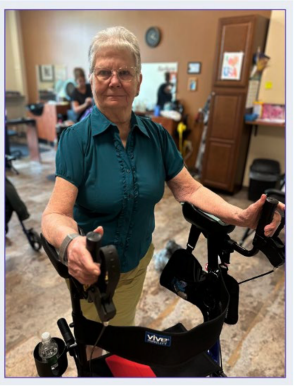
PACE participant Ben Lewis is thrilled with his new walker, provided by the PACE Durable Medical Equipment Department. His previous one was hard to use and didn’t support him well. With this one, he is able to move more easily, and he’s lost some weight.

“Before joining PACE, I would sit in my apartment all day long. I had a hard time moving and taking care of myself. This walker really helps—and PACE got it to me quickly after I enrolled!”

Ben visits the day center three days a week, where he receives meals, catches up with friends, participates in group activities like BINGO and karaoke, and participates in an exercise program that has helped improve his health.

He says he appreciates the transportation provided by PACE that makes it easy to get to the day center and the help he now receives at home from personal care aides. “I have people come to my apartment to help me take care of myself. Before, I couldn’t change myself and had problems with simple things like cleaning the kitchen and doing laundry. Now, I have the help I need, and my life is so much better. I’m so thankful for my PACE program.”

Betty – PACE is the Highlight of the Week



Betty lives in New York alone without any family nearby. She relies on online grocery shopping and in-home care for support.

PACE has provided Betty with a space to socialize, receive medical care, and participate in activities. The care she has received alongside the transportation services PACE has offered has created a support system and community for her in New York.

“If it weren’t for PACE, I would stay at home by myself. I come to the PACE day center to socialize, receive medical care, and I even get my hair done here! I am so thankful for the kind PAEC bus drivers who make it possible for me to be here each week.”

The Arc Oneida-Lewis Chapter A chapter of The Arc New York

"I'm Robert Hirt, and I'm proof that HCBS works!"

Pre and Post-Secondary Education Success



In middle school, he was introduced to School-to-Work, a group of programs provided by The Arc, Oneida-Lewis Chapter. "They taught me how to cook and how to count change. I visited, and I explored a lot of different jobs in the community," said Robert. From there it was on to CollegeWorks - a post-secondary college experience of The Arc, housed at Mohawk Valley Community College in Utica. "That's where things really took off for me. I was excited when I got accepted because I could keep busy and hang out with a lot of new friends. I did an internship, and I learned a lot on the job site." Robert was able to blend in with the rest of the College community, taking advantage of all the amenities and campus activities afforded to all students. "Visiting the library and going swimming. And if you get close to people, you make a bond that's never breaking," added Hirt.



Ready, Willing, and Able to Join the Workforce

After his graduation in 2017, Robert searched for competitive employment in the community. Success wasn't instantaneous. He applied and searched for a job for the better part of two years. In 2019, with assistance from The Arc's Supported Employment program, Robert learned of an opening at Progress Industries, an integrated business enterprise of The Arc.

"I'm happy they accepted me here. I make minimum wage, and I look forward to getting my paycheck. You don't earn money sitting around. This is a hard-working job." For Robert, it's more than work; it's a purpose and a way to be a contributing member to his community. "The people at my job are really friendly and understanding. They're like my family."

Eager to Take Center Stage

Because Robert has met so many people, it has led to other opportunities and experiences he says he wouldn't have known about. One of those is StageWorks, another program at The Arc. Designed to provide awareness, inclusion, and opportunities for people with disabilities with interests and talents in the creative and performing arts. "I found out from someone I met at CollegeWorks. When she told me about StageWorks, I said, 'Why not get up on stage and try some acting?





You get to dress up in costumes, you get to sing a lot, and [the people in the audience] always have a smile on their faces." Robert also regularly accesses the Night Rec program through Community and Family Services, where people go out into the community to eat, go to the movies, attend sporting events, shop, or engage in other leisure activities. "These programs are a lifeline for me and my friends," says Robert.

Proof Positive That HCBS Works

When asked how his life would be different today without them, he offers this: "If there were no more programs, then it wouldn't keep people occupied. I would be bored. These programs get kids away from the video games and out in the community to meet new people."



Today, Robert is a shining success and example of what supports, services, and opportunities have done for him over time. He continues to work and thrive at Progress Industries, and was even asked to speak at the 2023 CollegeWorks graduation ceremony as a graduate success. "They need more programs, people love these programs, and if there were more, then everyone would have something to achieve. They have been life changing for me."

Senate Special Committee on Aging:

A Very Special Place, Inc is a not for profit located in New York and I have worked in the field of IDD for over 30 years and have had the great pleasure of providing to support to people in the field some who require little to no oversight where they live in their own apartment or home with Com Hab, Supportive Apartments to Supervised IRAs. Those who are fully employed, with coaches or those who need daily support in life and attend Day Habs.

When it comes to aging the most prominent story we can tell is one of a gentleman, for the purpose of this writing I will call Sam. Sam lived at home with his family and through the Day hab program gained the skill set to move into a Supportive Apartment with minimal staffing and 2 roommates in the apartment. He utilized supportive employment 2 days a week and 3 days a week in Day Hab to continue expanding his skills. At the age of 38 his friends from his apartment and program came to us and stated something was going on with Sam he needed assistance with dressing, remembering he was cooking, getting ready for work, etc. After a few appointments it became clear he had the onset of dementia/Alzheimer's.

Sam now required a higher level of care, we assisted him into moving into one of our Supervised IRA's where there would be 24-hour staffing, he could no longer work and would be very agitated or confused with people he did not know. His comfort and memory were better in his Day Hab program with the routine and familiar faces. He currently attends and has difficulty but with full staffing and his friends he still participates to the best of his abilities in the community, with learning, and having fun. It is 5 years since his symptoms started and while he continues to regress by forgetting how to walk, talk, eat at times direct care staff and the nurses work with him daily at home and in program to assist him in maintaining as much as he can.

At all stages in life everyone needs assistance and we have seen here at AVSP, Inc more and more those with IDD/downs syndrome having dementia/Alzheimer's begin by 40. This creates a larger challenge for all. While they may have been very independent prior, the skill set declines and declines quickly. However with routine, friends and consistent staffing by going to program, being in a supervised setting that is conducive to not only dementia/Alzheimer's but to IDD field their life is still productive and inclusive.

The challenges we face are that so many want to close the programs and supervise IRAs, yet where do people like Sam go? Family is unable to care for him as they are older, and he becomes agitated and at times aggressive when he is confused with daily tasks. Does he go to a nursing home where the level of care for those with both IDD and dementia are not

provided the same level of support and knowledge as being in the Day Hab or the Supervised IRA?

OPWDD and the state need to realize if person centered then at each stage in a person's life the need, level of care and the friendships with those they live, work or attend program with assist in making their life fuller.

Aging does not mean a certain age when someone is considered older, it is when the need for assistance is greater and like everyone in life this may require staff, aid, supportive living, a home, etc. No one should have a choice in where they want to live and what they want to do during the day/evening. We request that the committee look at the whole picture of someone's life and all the level of challenges a person with IDD may face and ask them what they want, what works best to assist them. Speak to the families and the staff of people who receive all different types of services at different points in the persons life so a full option of choices and opportunities can be made available.

Thank you

Jacqueline Scarcella

Executive Director

AVSP, Inc.

The Harry and Jeanette
Weinberg Center for Elder Justice
AT THE HEBREW HOME AT RIVERDALE

Testimony for the Senate Special Committee on Aging Hearing

December 8, 2025

Thank you for the opportunity to submit this statement. I'm writing on behalf of The Harry and Jeanette Weinberg Center for Elder Justice at the Hebrew Home at Riverdale. We are the nation's first elder abuse shelter and a specialized safe haven for older adults experiencing harm. For more than twenty years, our mission has been to step in where systems fall short, filling the gaps that too often leave older adults with nowhere to turn when safety, stability, and independence are at risk.

As the Senate Committee examines the importance of community living and Home and Community-Based Services (HCBS), it is critical to recognize that elder abuse is one of the most profound threats to an older adult's ability to age in place. Abuse in later life is not rare, and it is not benign. Globally, it is estimated that 1 in 6 older adults experience some form of elder abuse each year[1]. It strips older adults of the very tools they need to remain in their communities: financial security, housing, social supports, medical care, autonomy, and the confidence that the people around them can be trusted. Financial exploitation alone accounts for an estimated $28.3 billion stolen from older adults in the United States each year, draining the very resources required for safe, stable community living.[2] For many of the individuals we work with, abuse is what pushes them out of their homes. It is not age or illness, but the absence of a safety net that understands their unique needs.

Elder abuse often occurs within relationships of dependency: intimate partners, adult children, grandchildren, caregivers, or others who control access to food, medications, transportation, or income. When the person who helps you get dressed or manages your Social Security check is also the person causing harm, the path to safety becomes extraordinarily complicated. This dynamic is what contributes to the invisibility of older survivors and is one reason abuse is so tragically underreported.

When older adults lose the ability to age in place due to abuse, the consequences are immediate and destabilizing. Survivors may be forced into institutional settings because there is no safe alternative in the community. Others may have no choice but to allow someone to move into their home under the guise of providing support, only to experience further exploitation. For individuals who have already lost financial resources, housing, or access to benefits because of abuse, even the most robust HCBS programs cannot bridge the gap alone. Community living is not sustainable without community safety.

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[1] "Abuse of Older People," *World Health Organization*, accessed November 24, 2025, https://www.who.int/news-room/fact-sheets/detail/abuse-of-older-people.
[2] "AARP Report Finds $28.3 Billion a Year is Stolen from U.S. Adults Over 60," *AARP*, accessed December 8, 2025, https://press.aarp.org/2023-06-15-AARP-Report-Finds-28-Billion-a-Year-is-Stolen-from-US-Adults-Over-60.

That is why elder justice must be understood as a core component of HCBS, not an auxiliary service. If the goal of HCBS is to preserve independence, dignity, and autonomy, then we must address the forces that erode these conditions. Elder justice interventions are health interventions, housing interventions, and community-stability interventions. They are integral to any system that aims to keep older adults safely connected to their communities.

At the Weinberg Center, our work is built around a coordinated, multidisciplinary response. The team is made up of attorneys, social workers, medical professionals, public health specialists, and community partners working together on every case to restore stability and rebuild safety. Our model is designed not only to interrupt harm, but to return older adults to the community whenever possible, with supports that reflect the full complexity of their lives. This includes our national network, the SPRiNG Alliance, which connects elder justice shelters across the country and strengthens the replication of this model so that no older adult is left without options.

We also know this model works. According to NYAM's 2024 evaluation of elder justice shelters, including the Weinberg Center, participants reported increased security, greater stability, and improvements in mental, physical, and financial well-being.[3] The evaluation demonstrates that this multidisciplinary model is effective because it stabilizes every domain of a survivor's life, including health, housing, finances, safety, and social support, rather than addressing any single issue in isolation. These are the precise conditions that make it possible for older adults to return safely to the community. Senator Gillibrand's recent report, *Age of Fraud: Scams Facing Our Nation's Seniors*, documents the escalating scale and sophistication of financial exploitation targeting older adults[4]. This report highlights the urgent need for coordinated elder justice interventions that prevent unnecessary institutionalization and strengthen community living. Her findings mirror what our experience has shown for years: when specialized elder abuse programs are available, older survivors can remain safely in their homes and communities.

But the need far exceeds the resources currently available. Across the country, elder abuse shelters and multidisciplinary elder justice programs remain limited, unevenly distributed, and often unsupported by federal funding streams. To meet the scale of the problem, we need dedicated federal investment in elder justice capacity-building, technical assistance, and shelter development, particularly within HCBS frameworks. Without this investment, older adults will continue to fall through the cracks, and the

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[3] "Need, Access, Impact, and Opportunities: Findings from a Multi-Site Evaluation of Elder Justice Shelters in the U.S." *NYAM*, accessed on December 8, 2025, https://theweinbergcenter.org/wp-content/uploads/2024/04/NYAM_CEAR_EJS_Evaluation_Report_Mar24_FINAL.pdf

[4] "Age of Fraud: Scams Facing Our Nation's Seniors." *U.S. Senate Special Committee on Aging*, accessed on December 3, 2025, https://www.aging.senate.gov/imo/media/doc/age_of_fraud_scams_facing_our_nations_seniors.pdf

The Harry and Jeanette
Weinberg Center for Elder Justice
AT THE HEBREW HOME AT RIVERDALE

promise of community living will remain out of reach for many of the people who need it most.

We also want to emphasize how important it is for the Senate to continue hearing from elder justice providers and survivors. Older adults experiencing abuse are among the least visible constituents in policy conversations, not because the need is small, but because the barriers to speaking out are so profound. Continued federal attention helps ensure that their experiences are not overlooked and that elder justice remains a priority in national aging policy.

Thank you again for the opportunity to share this perspective. Older adults deserve to live safely, independently, and with dignity in their communities. To realize that vision, elder justice must be recognized as essential to HCBS and the systems designed to support aging in America must fully reflect the needs of those most vulnerable to harm. We look forward to supporting the Committee's work in any way we can.

SPOP
SERVICE PROGRAM FOR OLDER PEOPLE

Testimony presented to the

U.S. Senate Special Committee on Aging

December 2025

Service Program for Older People
www.spop.org

I am Catherine Thurston, CEO of Service Program for Older People (SPOP), a community-based mental health center for older adults in New York City. Thank you for this opportunity to provide testimony to the U.S. Senate Special Committee on Aging on the importance of community living for older adults.

SPOP offers age-affirming mental healthcare to 1,000 individuals each year, with a goal to improve their overall health and ability to live in the community. We provide home and community-based services to older adults in New York City, including group-based psychiatric rehabilitation services, individual and group therapy, and psychiatry, all with a focus on supporting older adults in their desire to live in the community.

The most vulnerable individuals in our client population are those who live with a serious mental illness such as major depressive disorder, bipolar disorder, or schizophrenia. We offer a full-day program that provides psychiatric rehabilitation services focused on recovery, life skills, and personal goal-setting. The group meetings, goal-setting exercises, congregate meals, and other activities help to create a sense of belonging among these clients who tend to be most isolated and at risk for premature institutionalization.

One significant strength of the program is the fact that the minimum age for enrollment is 55; this means that participants are always with a peer cohort, rather than struggling to find common ground with teens or adults at a different stage of life. The program has been highly successful

in giving older adults – many with a long history of institutional care – the confidence and skills to live in the community.

Home and Community-Based Services (HCBS) have proven to be one of the most effective interventions in supporting older adults. Our families, cities, and towns are stronger when older adults are able to live in community with the services needed to keep them healthy, independent, and socially connected.

In closing, let me share a story about one SPOP client:

JJ, 66, was referred to SPOP's psychiatric rehabilitation program four years ago seeking support for major depressive disorder. She struggled to make eye contact and spoke in a small voice during the intake process, saying at one point that she was "joining this program because I feel like I am at the bottom of my well. I have no place to go but up." Her goal was to find employment and live on her own, and after several months she expressed interest in pursuing training as a mental health Peer Specialist. She was accepted at a competitive program and recently completed certification. She shared that "people should not feel ashamed or misunderstood. Society can make you feel so bad about your mental health and even doubt yourself. I want to help others find their voice like I did." She has now graduated from SPOP and is now proudly working at another agency as a Peer.

United States Senate Special Committee on Aging

Honor Rick Scott, Chair & Honorable Kirsten Gillibrand, Ranking Member

Submitted by: Kayleh Levy-Weller

December 8, 2025

Thank you, Chair Scott and Ranking Member Gillibrand, and members of the Senate Special Committee on Aging for holding this hearing and for the opportunity to submit testimony. My name is Kayleh Levy-Weller, and I am the Lead for Strategic Planning and Grants in the Caring Department at UJA-Federation of New York.

Established more than 100 years ago, UJA-Federation of New York is one of the nation's largest local philanthropies. Central to UJA's mission is to care for those in need—identifying and meeting the needs of New Yorkers of all backgrounds and Jews everywhere. UJA supports an expansive network of nearly 100 nonprofit organizations serving those that are most vulnerable and in need of programs and services and allocates roughly $200 million each year to support older adults, combat poverty and food insecurity, nurture mental health and well-being, strengthen Jewish life, and respond to crises here and across the globe.

UJA-Federation of New York supports a range of community-based initiatives that help older adults and people with disabilities remain socially connected, engaged, and able to live independently. Five programs in particular—**Verve 55+ Living**, **Social RX**, **UJA on the Way**, our **Benefits Navigation Initiative,** and the **N/NORC Program**—demonstrate how targeted social supports, proactive outreach, and practical assistance contribute to stronger community living and prevent unnecessary institutionalization.

Verve 55+ Living: Reducing Isolation Through Connection and Purposeful Engagement
Verve 55+ Living operates at four community centers in the New York suburbs—two in Westchester and two on Long Island—to foster meaningful engagement among adults aged 55 and older. Each location employs a dedicated professional who develops high-quality cultural, educational, wellness, and social programming designed for this life stage. Activities such as arts workshops, food-based programs, group hikes, and weekly meetups help participants build friendships, strengthen social networks, and reduce loneliness.

One widower on Long Island shared that after losing his wife—his primary source of daily companionship—he struggled with profound isolation. Through Verve 55+, he joined a men's group where he found both support and friendship. He later became a regular participant in a weekly "What to Do in Retirement" circle, where older adults discuss the joys and challenges of navigating a new chapter of life. These programs provided him with a renewed sense of purpose and connection at a vulnerable moment.

Social RX: Identifying Isolation and Navigating Complex Systems
Through the Social RX initiative, community centers employ Connection Specialists who proactively identify isolated older adults and serve as trusted guides through health, social service, and community systems. Specialists maintain relationships with hospitals, government agencies, mental health providers, transportation programs, and local nonprofits, ensuring that individuals can be connected to the right supports at the right time.

A striking example comes from a group of four older adults on Long Island who were experiencing extreme loneliness—so much so that they regularly checked into their local emergency rooms on weekends simply to be around people. Hospital staff, who affectionately but worriedly referred to them as "frequent flyers," ultimately referred them to Social RX. Through consistent outreach, social connection, and coordinated support, these individuals are now building relationships and engaging in programming that reduces their isolation. Their improved well-being has also reduced unnecessary ER utilization and eased pressure on hospital systems already facing staffing shortages.

Connection Specialists help address exactly these kinds of challenges—loneliness, transportation barriers, difficulty securing home care, confusion around benefits, and caregiver strain—which, if unaddressed, lead to avoidable crises and increased institutional care.

UJA on the Way: Overcoming Transportation Barriers to Community Participation
Transportation is one of the most significant obstacles to community living in suburban regions, especially for older adults and people with disabilities. Launched in 2025, UJA on the Way is a coordinated ride-access initiative developed in partnership with community centers across Long Island and Westchester.

The program provides reliable transportation to local programs, volunteer opportunities, social gatherings, and community activities through partnerships with taxi companies, rideshare platforms, and agency-operated accessible vans. Staff at each center assist participants with booking rides, coordinating schedules, and maintaining regular outreach.

For a group of young women with autism living in Westchester, transportation had long been the primary barrier preventing them from joining community programs. Through UJA on the Way,

they now travel independently to weekly activities where they build social skills and friendships. A single transportation solution dramatically expanded their opportunities for community participation.

Benefits Navigation: A Critical Foundation for Independent Living
Maintaining independence often requires sustained access to Medicaid, SNAP, early intervention services, employment supports, and other benefits—yet the systems governing these supports are often confusing and burdensome. Many older adults and people with disabilities lose vital services not because they are ineligible, but because forms are difficult to complete, communication is inaccessible, or recertification requirements are unclear.

UJA-Federation's Differing Abilities Committee identified a deep need for benefits navigation and systems guidance across the disability and caregiver community. In response, UJA-Federation is investing in benefits-navigation professionals at three community centers who assist individuals and families in accessing government benefits, understanding school-based supports, identifying employment pathways, and securing respite and caregiver resources. One family in an Orthodox Jewish community—fearful of stigma and unsure how to advocate for their son—struggled for years to understand the special education supports available to him. Through the benefits-navigation program, they received technical case management and peer support to navigate the IEP process, helping them secure the services their son needed to thrive.

N/NORC Program
Naturally Occurring Retirement Communities (NORCs) and Neighborhood Naturally Occurring Retirement Communities (NNORCs) – collectively referred to as N/NORCs – are multi-age housing developments or neighborhoods, respectively, that were not originally developed for older adults but are now home to a significant number (at least 40%) of older people. N/NORCs were founded more than 40 years ago with the goal of transforming residential complexes and neighborhoods to meet the needs of a growing cohort of older residents and enable them to remain living independently in their homes, thrive in their communities, and delay hospitalization or nursing home placement.

N/NORC programs provide case management services, nursing services, recreational, social and cultural activities, volunteer opportunities, and ancillary services tailored to meet the needs of each community. By providing culturally and linguistically diverse staff to administer wellness checks and organize community activities, N/NORCs provide both support to individuals struggling with social isolation while simultaneously working to actively combat this phenomenon with intentional opportunities to connect. This makes N/NORCs an integral part of the combatting social isolation landscape.

One powerful example comes from a 94-year-old resident of the Penn South NORC in Chelsea—the first NORC in the United States. For years, she found joy in the community's classes, discussions, and social gatherings, but as her memory declined, she began withdrawing from activities she once loved. Traditional programming no longer felt accessible to her, and she and her loved ones worried she would lose the connections that anchored her to her community.

Through the NORC's dementia-friendly programming—designed specifically to support individuals with cognitive changes—staff were able to help her remain engaged. With tailored activities, trained facilitators, and an environment that prioritizes dignity and inclusion, she now participates fully in programs that are structured for her needs. This support has allowed her to maintain social ties, preserve a sense of belonging, and continue living safely and meaningfully in the community she has called home for decades.

Conclusion

Verve 55+ Living, Social RX, UJA on the Way, UJA-Federation's benefits-navigation initiative, and the N/NORC Program all reinforce the same principle: community living requires dependable social connection, reliable mobility, and clear pathways to essential supports. These programs help older adults and people with disabilities maintain independence, prevent isolation, and participate fully in community life.

We urge Congress to invest in social connection initiatives, transportation access, HCBS infrastructure, and benefits navigation so that individuals across the age and disability spectrum can continue to live safely and meaningfully in their communities.

Testimony November 3, 2025 Assembly Standing Committee on People with Disabilities

Good morning, and thank you for the opportunity to speak at this hearing.

My name is Dr. Susan Lucas, and I am a parent and advocate for individuals with intellectual and developmental disabilities. I recently retired from my profession as a physical therapist, but I am now dedicating my time and energy to making the lives of my daughter — and others like her — better. I currently serve as President of the Board of Directors for The Arc Mid-Hudson, which provides services across Putnam, Ulster, and Greene Counties. I also serve on several committees at the New York State Arc, most notably the Advocacy Committee — which is why I'm here today. I last spoke before this body in October 2021, when the topic was employment and how to help individuals with disabilities enter the workforce. Today's hearing, however, strikes at something even more personal — where people live. It's something most of us take for granted, but for individuals with I/DD, residential choice is often limited or entirely out of reach.

Let me share my family's story.

My daughter Eileen is 42 years old. She contracted a Group B Strep infection from me at birth — an infection that today would likely be prevented through routine screening and treatment. Unfortunately, at that time it caused complete frontal-lobe brain damage. Eileen doesn't have a visible physical disability, but she functions at the level of a kindergartener. She will never read, drive a car, get married, or live independently.

When Eileen was 12, I was strongly advised to place her on the State housing list. At the time, I found the suggestion deeply upsetting — as if I were being asked to plan for something I wasn't emotionally ready to face. But it turned out to be wise advice. Years later, when Eileen was 29 — and her four siblings had moved out on their own — a placement became available at an Individualized Residential Alternative (IRA) close to home. With Eileen fully involved in the decision, she moved into a house with nine other women. She was excited. She told me she wanted to "be on her own," just like her brothers and sisters. This coming January marks 15 years that Eileen has lived in that home.

I share this story to make a few important points.

First, things have changed over the years — and not always for the better. Eileen has never had her own bedroom. She's shared a room with another resident for 15 years, and there's no opportunity in sight for her to have her own space. We all understand how important privacy and autonomy are. We expect a door we can close, a space that's ours. Eileen doesn't have that choice. Now, I am grateful that she is safe, cared for, and supported by compassionate staff. But if she ever decided to leave that home, she'd likely never get back in — because she is

considered “too high functioning.” Please remember that phrase: too high functioning to get in, but not independent enough to live alone.

Then there’s the issue of staffing. Years ago, staff were able to take residents on trips — even to Disney World. Now, Eileen is lucky to go to the Dollar Store. Limited staff means limited outings, limited experiences, and limited joy. Thankfully, we live nearby and can take her home on weekends to be with family. Many other residents don’t have that luxury.

Finally, many of these homes are aging and in need of infrastructure upgrades. Providers face mountains of red tape just to make necessary repairs or improvements.

Second, I want to talk about the Certified Residential Opportunities list — the CRO list.

Families seeking residential placements must go through a lengthy OPWDD process that categorizes need as Emergency, Substantial, or Current. I’m often contacted by families who are heartbroken and frustrated. Their adult children may be “too high functioning” to qualify, yet these parents are aging, struggling, and living in fear of what will happen when they can no longer provide care. One mother told me, “I’ll have to die or have a catastrophic illness before my daughter will get housing.” We hear that there’s a “wait list” — or that there isn’t one. Which is it? What we do know is that homes are closing, both state-run and private, primarily due to staff shortages.

The result is a cruel paradox: people desperately waiting for homes, and homes sitting empty because there’s no staff to open them.

From a provider perspective, The Arc Mid-Hudson currently has 27 open beds — that’s 27 people who could be served today — but we can’t fill them because we lack the workforce.

This translates to over $4 million in lost revenue each year. That’s money that could go toward better staff wages, more stability, and less turnover. Each month, we receive 30 to 60 referrals from OPWDD, many from across the state, not necessarily from our service counties. Often, these referrals are inappropriate — individuals whose needs exceed what the agency can safely provide. When a placement finally is offered, families sometimes decline because the available home is hours away from where they live. The natural family unit suffers, and the bed remains empty. The system isn’t working efficiently — not for families, not for providers, and certainly not for the individuals it’s supposed to serve.

So, my ask today is simple but urgent:

First, make residential housing available to all individuals with I/DD — not only those in crisis. Prevention is more compassionate and cost-effective than waiting for emergencies.

Second, ensure that every individual has the dignity of their own bedroom. Privacy is not a privilege; it's a human need.

Third, invest in the workforce. Without competitive wages for direct support professionals, homes cannot function — and empty beds will continue to waste both opportunity and resources. Make the model work well, rather than assume alternatives are sufficient.

Finally, streamline the referral and placement process so individuals can live near their families and communities, not halfway across the state.

The Arc Mid-Hudson and organizations like it are ready to help solve this crisis. We have the homes, the commitment, and the expertise — but we need the State's partnership and investment to make it possible. The OPWDD 2023-2027 Strategic Plan noted an "insufficiency of housing and emergency response/crisis" is a challenge.

My daughter Eileen, and thousands like her across New York, deserve what we all want: a safe home, caring support, and the chance to live as independently and meaningfully as possible in the community they call home.

Thank you for your time and your continued attention to this deeply personal and profoundly important issue.

Testimony of Stanfort Perry,
CEO, AHRC Nassau and Citizens Options Unlimited

United States Senate Special Committee on Aging Hearing:
Home- and Community-Based Services

December 8, 2025

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Thank you for the opportunity to share written testimony about home- and community-based services (HCBS) and their support of older adults with intellectual and developmental disabilities (IDD) to participate in the community.

My name is Stanfort Perry, and I serve as Chief Executive Officer of disability services agencies, AHRC Nassau, a chapter of The Arc New York, and Citizens Options Unlimited. I have dedicated my career to providing people with intellectual and developmental disabilities a lifetime of quality supports and now oversee the operation of the largest residential services network in New York State.

I. Changing Population, Challenging Funding Landscape

There's a service flashpoint coming. The community-living models created about forty years ago[1] for people with IDD to thrive and flourish are challenged in responding to the increasingly complex needs of a population that is growing older.

The number of people served by Long-Term Services and Supports from state IDD agencies increased by 80% from 2000 to 2020.[2] At the same time, people's needs are being

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identified more precisely through refined medical understanding, such as increased autism diagnoses[3] and dual-diagnoses of IDD with co-occurring mental health conditions.[4]

As a consequence of these advancements, service providers can identify higher behavioral and clinical needs. Yet, they are struggling in real time to retool programs — to bridge the gaps of what these models were originally designed to do, what people actually need, and what Medicaid funding supports.

A primary HCBS example of this service bottleneck is New York State's ongoing waiting list for Certified Residential Opportunities (CRO) or placements in Medicaid-funded residences.[5] Priority status is given for the emergency placement of people with co-occurring mental health and behavioral needs. Higher levels of care require additional resources outside current reimbursement structures (e.g., more frequent emergency room visits, psychiatric services, and increased staffing ratios).

The changing population makes it difficult for agencies to keep pace with the need. Moving forward successfully will require data-informed decisions and more proactive service models to reflect the current needs of this population.

II. Aging in Place, Difficult Under Current HCBS System

As people with IDD age, they face the same chronic conditions as the typical population.[6] However, the IDD population experiences additional complications: "unrecognized or poorly managed health conditions (e.g., visual and hearing impairments, mental health problems) and higher rates of morbidity and mortality than the general population."[7]

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Roz had a medical crisis in 2013 requiring extensive surgery, a feeding tube, and rehabilitation.

Due to Roz's increased medical needs and a lack of relevant HCBS funding, she was not able to return to living independently. She had to leave her friends and neighbors and eventually transition to an ICF because appropriate supports were not available to her through current reimbursement models.

Continuity of care within a service network helped Roz maintain her health, after she had difficulty speaking, bathing independently, and began using a custom tilt wheelchair. Roz, like many people with IDD, relied on long-time staff and her guardians to advocate for her needs.

Roz says she feels young at heart most days, yet current community-living models were not initially set up with the expectation that people like Roz would lead long lives. Many HCBS residences on Long Island were purchased about 40 years ago without this expectation. Consequently, Individualized Residential Alternatives (IRAs), such as group homes or apartments, may lack barrier-free accessibility — multiple levels without ramps, narrow doorways, inaccessible bathrooms, and need for modifications like walk-in showers or handrails in the bathroom.

The focus on deinstitutionalization and progression into community living was then bold and innovative. Now, however, the costs of keeping people aging safely in place can be cost-prohibitive for agencies and limit access to full participation in the community.

While agencies are funded for continuum of care, IRAs are not set up for higher levels of need. One-to-one staffing or nursing are possible supports, but not reimbursable.

III. Age and Life Stage Not Accounted in HCBS Reimbursements

Smaller providers and programs are closing because of inadequate reimbursements, rising

operational costs, the effect of inflation, and an escalating staffing crisis[8] across the country. Effective billing by agencies has never been more important. Yet, agencies struggle within these constraints to balance funding needs with the interests and preferences of older people.

David Markowitz, a resident of an AHRC Nassau group home, will turn 98 in February. He would like to retire. He can't because of larger funding and staffing issues. For David to stay at home he would need to be enrolled in Community Habilitation where a Direct Support Professional (DSP) would provide individualized day services to him in his home or in the community. The issue becomes that due to limited staffing and high turnover, should a community habilitation worker not be present for the shift due to personal reasons or perhaps a vacancy in the position, the care would default to the provider. This, then, is not a reimbursable service, but falls to the provider to provide the care.

His daily schedule must fit into HCBS program buckets, like going to day program where he is encouraged to take part in an activity or socialize. He wants to be active but doesn't have the same interests as when he was younger and needs the flexibility to design a day that meets his needs with appropriate staffing that is reimbursed.

David remembers President Franklin Roosevelt speaking on the radio. He was part of the first wave of people leaving their families to live in group homes and working on the assembly line at a sheltered workshop.

Today, David experiences mobility issues and chronic discomfort that comes from age, like arthritis, stomach issues, and headaches. He is still active and healthy – but most enjoys reading the morning paper and visiting his local diner.

David's continued health and independence rely on HCBS for consistent staffing and institutional knowledge. Even supported by people who understand how he communicates and his preferences, there are limits. Our current reimbursement structure prevents the creation of a reimbursable person-centered plan that fully meet David's needs.

IV. Growing Older at Home, Without Services

There are a number of parents of advanced age who are just starting to consider community-living settings for their aging children. Research shows parents caring for adult children with IDD into their older years have "poorer health and well-being;" those, living

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with their children, “are a particularly vulnerable group. At age 71, these parents had poorer psychological well-being, more physical health symptoms, greater obesity, and fewer visits with friends or relatives.”[9]

This conversation will soon be impacting agencies around the country as “around 75% of adults with a disability live with an aging parent or other caregiver, and most are not connected to public supports or services. As a result, aging parents and family members frequently serve as unpaid primary caregivers for their family member with I/DD.”[10]

The importance of planning what happens after primary family members pass can be challenging and leads to increased reliance on continuity of care in later years.

As people with disabilities age out of their family homes, different types of residential supports will be needed and new billing systems. The difference between HCBS and ICF funding models can be stark — whereas HCBS is waiver-based funding for smaller community settings (IRAs) with services provided in the community, ICFs have “all-in-one” bundled rate system, with built-in services, such as 24/7 staffing and nursing supports, physical therapy, medical care, and nutrition services.

A more nuanced funding approach is urgently needed that takes into consideration diverse medical needs and supports that arise from aging. Sometimes, it is not as straightforward as David or Roz’s experiences but requires more flexible funding structures to adapt services and provide true accommodations as people grow older.

V. Education and Awareness for Families, Medical Providers

For families, it can come as a shock when people with IDD experience age-related health challenges earlier in life from “biological factors related to syndromes and associated developmental disabilities, limited access to adequate health care, and lifestyle and

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Marianne Barbera, a retired teacher, lost her sister, Susan Auletta, in 2021. Susan was 53 when she passed away due to age-related decline typical for people with Down Syndrome. Over the course of five and a half years, Susan — who had loved telling jokes, was proficient in sign-language, dancing, and being the life of the party — lost her speech, mobility, experienced debilitating seizures, and became completely reliant on others.

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Marianne likens the onset of Susan's dementia to holding hands with her sister and seeing a tractor trailer headed their way. In tribute to her sister, Marianne is an active advocate bringing attention to the issue of aging with disability and volunteering weekly at AHRC Nassau. Marianne teaches music and movement knowing how her sister thrived when engaged — and how activities that are tailored to people's interests unlock memories and build connections.

VI. Conclusion

The long-term viability of home- and community-based services has become a growing concern. It's time to build on the lessons learned over the decades of community living and use all of our data, lived experience, and technology to advance a bold, new plan for the future.

What is needed is not only a funding structure that is flexible to meet the needs of a changing and aging population, but a real investment in service providers.

Rather than relying on shifting state investments, the federal government should dedicate a steady funding stream focused on the needs of people with IDD. An area to start would be to move forward the "Recognizing the Role of Direct Support Professionals (DSPs) Act"

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(H.R.6137[12], S.3211[13]) or similar legislation, which requires the Office of Management and Budget to consider updating the Standard Occupational Classification (SOC) and recognizing the DSP role as a distinct profession. This leads to data collection and ideally more robust funding.

Thank you for your consideration of how to build funding and services to advance the health, independence, and inclusion of aging adults with developmental disabilities.

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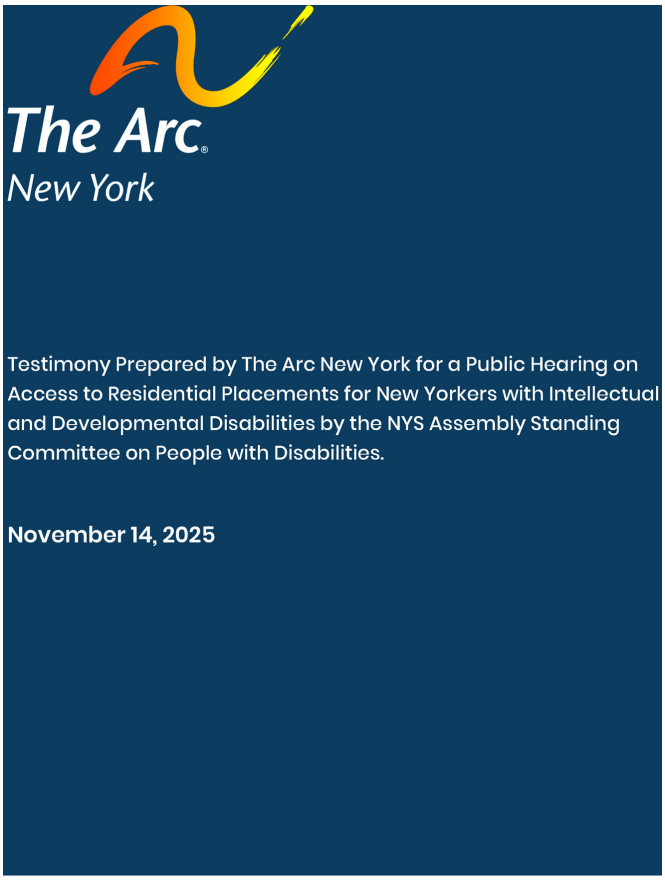
Thank you for your consideration of how to build funding and services to advance the health, independence, and inclusion of aging adults with developmental disabilities.

[12] United States, Congress, House. Recognizing the Role of Direct Support Professionals Act. Congress.gov., www.congress.gov/bill/119th-congress/house-bill/6137. 119th Congress, 1st session, House Resolution 6137, introduced 19 November 2025. Accessed 8 Dec. 2025.

[13] United States, Congress, Senate. A Bill to Require the Office of Management and Budget to Consider Revising the Standard Occupational Classification System to Establish a Separate Code for Direct Support Professionals, and for Other Purposes. Congress.gov., https://www.congress.gov/bill/119th-congress/senate-bill/3211. 119th Congress, 1st session Senate Bill S.3211, introduced 19 November 2025. Accessed 8 Dec. 2025.


The Arc
New York
Testimony Prepared by The Arc New York for a Public Hearing on Access to Residential Placements for New Yorkers with Intellectual and Developmental Disabilities by the NYS Assembly Standing Committee on People with Disabilities.
November 14, 2025

The Arc New York

The Arc New York Written Testimony

Access to Residential Placements for New Yorkers with Intellectual and Developmental Disabilities by the NYS Assembly Standing Committee on People with Disabilities.

November 14, 2025

Introduction

Assembly Standing Committee on People with Disabilities Chair Assemblyman Santabarbara, Ranker Assemblywoman Jodi Giglio and members of the committee, thank you for the opportunity to provide feedback on access to residential placements for New Yorkers with intellectual and developmental disabilities (IDD) and its impact on our field and the people we support.

The Arc New York is a family-led organization with a 75-year history working toward our mission to "provide people with intellectual, developmental, and other disabilities the ordinary and extraordinary opportunities of life." Our organization is the largest provider of supports and services for New Yorkers with intellectual and developmental disabilities in the state. With 35 operating Chapters across New York state, The Arc New York supports more than 60,000 individuals and families in every county of the state and employs more than 30,000 people statewide.

The parents who created our organization were among the earliest advocates for quality services and opportunities for people with IDD. In the over 75 years since our founding, we have witnessed – and at many times driven – massive transformation and progress in our field. Over those seven decades, New York has developed a robust system of comprehensive individualized services and programs that aid independence, support families, and emphasize inclusion in communities.

We have long advocated for recognition of our essential frontline staff, sustainable investment, and common-sense policy. For over a decade preceding the current administration, that call went largely unheard. Governor Hochul has put forth new investments every year under her tenure, which have demonstrated a renewed recognition of the needs of New Yorkers with IDD. While these investments are a start, significant needs remain to right our system after years of neglect.

The Arc New York provides advocacy, residential supports, day services, employment programs, respite services, education and clinical care for New Yorkers with IDD. Today, we face a crisis of access to safe, appropriate, and person-centered residential placements. Based on voluntary provider data and estimates, thousands of individuals and families remain on waiting lists—often for years—because our system lacks the workforce, funding, and infrastructure necessary to meet their needs.

Acknowledgment of Support and Existing Barriers

According to the Office for People with Developmental Disabilities (OPWDD) Administrative Directive Memo 24-ADM-03, the residential placement process "is designed to facilitate sustainable, equitable, and accessible housing and residential supports...and to ensure availability of services for those in greatest need." We genuinely believe OPWDD shares our goals and the goals of people and families to find appropriate residential supports for New Yorkers with disabilities.

OPWDD is fully aware of the challenges around the current residential placement process and its barriers. They have taken steps to begin to address it by including significant additional rate investments at the end of 2024, technical assistance and support for behavioral challenges of people currently supported in voluntary residences, amendments to its Certified Residential Opportunity process, and additional payments offered to providers to support placement of individuals off the Residential Needs List.

The current administration and OPWDD leadership have demonstrated their commitment to improving supports for New Yorkers with IDD. The Governor and legislature have made investments after more than a decade of stagnant funding, and the Commissioner is fully engaged and collaborative, working tirelessly to identify and address operational concerns.

We deeply appreciate both the investment and the partnership.

But the reality remains: We are failing to meet the needs of thousands of New Yorkers with IDD who require support in certified residential placement. The residential placement process needs modernization and reform and our care system continues to need meaningful and sustained investment.

Overview of Challenges Facing Residential Access

Thousands of New York state citizens with IDD are waiting for placement in a community residential setting, and many are in emergency/immediate need. The state has not provided an adequate way for families to plan when providing care at home becomes difficult or impossible. People with IDD and their families face a long and uncertain placement process, without a clear understanding of that process or the extent of their wait—and while thousands await suitable placements, many existing openings go unfilled.

Ongoing staffing challenges limit our ability to safely support people with complex medical and behavioral needs, and we have inadequate resources to upgrade or modify homes limit our ability to offer suitable settings for all people in need of placement.

In practice, most placements occur through emergency referrals. This makes it nearly impossible to ensure people are placed in the most appropriate, least restrictive home environment, and limits their choice in their own housing and the opportunity to achieve as much independence as possible.

The current residential placement process results in unnecessary long-term vacancies in the voluntary sector, causing significant and unsustainable deficits for providers, and leaving thousands of people without the residential support they need.

The systemic issues with access to residential placement fall into three main areas: transparency, flexibility, and resources.

Transparency

It is important to note that a person can only be considered for residential services after all options for supporting them in their current home or another non-certified setting have been explored, documented, and exhausted. A person is only added to

the Certified Residential Opportunities (CRO) list if the state determines their needs cannot be met in an alternate setting.

There is currently no way for providers to access the complete CRO lists without request from their Developmental Disability Regional Office (DDRO). Statewide and regional data on residential need is not shared regularly or openly.

The full scope and number of people currently awaiting residential placement, or how long they have been waiting and information about individual demographics and need is inconsistently available and at times incomplete and/or unclear. We also do not know the number or characteristics of residential vacancies available across the state.

We estimate that there are approximately 5,000 people on the Residential Needs list today, and approximately 2,000-3,000 residential vacancies are available at providers across the state. However, we have no way of verifying the number of people on the list, and that is a big part of the problem. Without a clear understanding of these demographics, we cannot develop a unified strategy to address the need that exists today, or the anticipated need for the future. We would support legislation that requires OPWDD to report data on the number of people on the Residential Needs list, their demographics, support needs, time on the list, and region where they reside or are seeking placement.

Flexibility

When people are placed on the list, they are assigned a need level: Emergency Need, Substantial Need, or Current Need. People in the emergency need category are in immediate crisis. They have no stable place to live, are at imminent risk of homelessness, or face urgent threats to their health and safety or the safety of others. These people require immediate placement to ensure their basic safety and care.

People in the Substantial Need category are at rising risk of crisis. Their caregivers may be increasingly unable to meet their support needs, or risk to their safety or the safety of others is escalating. Placement of people in the Substantial Need category prevents these situations from deteriorating into emergencies.

People in the Current Need category are ready and waiting for certified residential placement, but do not face imminent danger. These are the people our system is

intended to plan ahead for — ensuring smooth, person-centered transitions before crisis hits.

We fully recognize the importance of prioritizing Emergency Need. There is no question that people cannot be left in crisis situations. However, what should be a proactive, planned system for residential care has become entirely crisis-driven.

To find placements, providers are sent residential referral packets selected by their DDRO or by provider request. Providers then review the profiles to determine if they can appropriately support that person in one of their open residential placements.

If no suitable placement is available, it is not because providers do not want to support them. Often, the care needs and behaviors of the people referred for placement are not compatible with available opportunities. The vacancy may be in a two-story home, and the person uses a wheelchair. It may be in a home of all older women, and the new resident is a young man. Or, a provider simply may not have the staff or resources to meet individual's specific or complex needs. These are reasons why a provider may not be able to support the individual, but the opening also has to be desirable and appropriate from both the family and the individual's perspective as well.

We strive to place as many people as possible in the most appropriate setting. The safety and well-being of the people we support is of utmost importance.

Often, people on the Emergency Need list require complex medical care or intensive behavioral interventions. It is simply more challenging to find appropriate placements for people with extremely high needs, but in many cases, the only referrals a provider receives are for people on the Emergency Needs list.

There have been recent improvements to this process, and providers are sometimes able to place referrals from the Substantial Need list. But it is critically important to understand that people from the Current Need list are rarely referred to providers for residential placement. These are people whose support needs the state has determined can *only* be met in a residential setting. But unless someone is in or nearing crisis, we rarely even consider a placement for them.

In some cases, we have vacancies that could be a wonderful fit, but without flexibility to fill them with people who are not in immediate crisis, the bed stays vacant, and people in the current need category continue waiting – indefinitely – for a home.

This represents a significant breakdown in our residential service system.

Resources

You have heard for years that our system is not adequately or sustainably funded. We went more than a decade with no increases – zero.

That is changing, and we appreciate it. Recent investments have demonstrated a positive shift in the state's commitment to people with disabilities. But to date, those investments don't even fully compensate for inflation over the past five years. We still do not have the resources needed to fulfill our mission for all New Yorkers with disabilities.

Fundamentally, there are not enough residential placements available to meet the needs of people waiting for services. Yes, we have vacancies, but if we filled them all tomorrow, thousands of people would still be waiting for homes.

The state needs to make capital investments to expand residential opportunities, and continue to make workforce investments to make sure we have staff to operate them.

We have finally been able to start raising wages that were stagnant for years, but direct care and clinical staff are still woefully undercompensated, and providers are not competitive in the employment market.

We need consistent staffing to operate homes. To safely support people with high needs, we need tenured direct care and clinical staff who can deliver complex medical care and implement challenging behavior plans.

Providers are sometimes hesitant to take on people with extremely high support needs, because they cannot be confident they will have the resources necessary to sustain those supports, or that alternatives will be available if a placement become untenable. Guaranteeing high-needs funding to align with the cost of high-needs care would allow us to fill more vacancies and support more people.

Nonprofit providers are not the only ones who are under-resourced. DDROs are responsible for managing residential referrals and maintaining an updated CRO list. They do so with minimal staff, using antiquated systems. They too need adequate resources to fulfill their role, and modern electronic solutions for managing a complex system of care.

Recommendations

So how do we do better? By improving transparency, flexibility and resources.

We are currently requesting a 2.7% Targeted Inflationary Increase (TII) in the New York state budget to correct for inflation over the past year and ensure funding accounts for the increased cost of living and providing services.

We have proposed a Careforce Affordability Initiative to support recruitment and retention with opportunities for affordable housing, childcare and healthcare for direct care staff. We have also put forward a Capital Funding and Infrastructure Plan to maintain and modernize programs and facilities, which would improve outcomes and save money.

Beyond our budget requests, we must consider:

- Expanding access to step-down facilities where people with immediate psychological and behavioral challenges can receive intensive support until they can be effectively supported by a community provider,
- Enhancing the role of OPWDD State Operated programs as the "provider of last resort," to ensure a safety net is available if a placement proves inappropriate.
- Examining the high-needs funding process to ensure providers are appropriately paid for intensive services,
- Improving the clinical competency of voluntary providers to handle more challenging referrals,
- Developing an efficient electronic management system that allows for partnership between nonprofit providers and the state, including access to complete, real-time information about people in need of placement, and
- Improving transparency by requiring annual reporting on residential waitlist size, duration, and demographics. Previous attempts had been made by the legislature to address this need, but it did not advance out of committee.

Conclusion

The crisis in residential supports for people with intellectual and developmental disabilities is not a problem of isolated inefficiency—it is a systemic issue that profoundly impacts thousands of New York families. Addressing this requires

sustained commitment to fair funding, workforce stabilization, transparent data, and person-centered planning.

New Yorkers with developmental disabilities have a right to a home and supports, which respect their dignity, independence, and choice. New York has a legal and ethical responsibility to provide those supports.

The Arc New York urges OPWDD to continue to partner with the provider community, governor and legislature in exploring strategies to address the needs of people in crisis, and to prevent others from slipping into crisis by better meeting current and future need.

We understand this is a complex topic, and we have additional recommendations. By holding this hearing, you have demonstrated your interest in improving access to residential services. We believe we can be strong partners in an ongoing dialogue about creative solutions to address these issues and better meet the needs of New Yorkers with disabilities, and we encourage you to continue this conversation.

The Importance of the HCBS Waiver to my family for submission to the Congressional Record

By Margaret Vogt

December 8, 2025

My name is Margaret Vogt. I live in southern Westchester where my daughter, Diana, receives services through the ARC Westchester, a chapter of NYSARC.

Because of extreme prematurity and severe lung complications, Diana has a very low IQ, multiple health issues and an anxiety disorder. She functions like a young child, cannot make decisions on her own or care for herself. She requires 24/7 supervision. During infancy and her school years, she lived at home with us and attended special education schools. Despite her loving disposition and zest for life, Diana's care was very challenging, requiring me to quit my job to look after her full time.

Diana is an only child. When she aged out of school, her father was already retired and we were both in our sixties. We were very worried about her future and our ability to care for her as we aged. Her nearest close relatives are in Virginia and Texas and none of them were (are) ready or able to meet her many needs in our absence.

Our first problem was what was she going to do all day as she in not capable of holding a job and I needed to return to work. Fortunately, the ARC Westchester found a place for her in one of their day habilitation programs. Diana spends her days in the community volunteering, learning new skill to build independence and socializing. She loves the program and the feeling of being useful, helping others and learning.

Several years later, ARC Westchester found a place in one of their community residences that fit Diana's needs. Now she lives in the community where she grew up. The ARC Westchester staff at the house keep her safe and meet her many medical and behavioral needs. As professionals in the field, they have been able to teach her skills that have built her independence beyond what her father and I hoped for (or were able to do ourselves). She has an active social life with her housemates and friends from the community.

Diana's father and I want Diana to be safe, happy and growing toward greater independence. Through the services she receives from the ARC Westchester, we feel she has a chance at that life. We will never stop worrying about her future. As long as we are able, we will stay very involved in her life. We do not expect peace of mind, but we do expect the United States of America to support and protect its most vulnerable citizens by funding HCBS waiver services.

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The Kennedy Willis Center
ON DOWN SYNDROME

December 8, 2025

Dear Chair and Members of the Committee,

I am writing to share the perspective of our agency on the importance of programs that allow people with disabilities and older adults to participate fully in their communities. These initiatives are not simply services; they are lifelines that foster dignity, independence, and belonging.

Community-based programs—whether they provide accessible transportation, inclusive recreational activities, or support for independent living—help ensure that older adults and individuals with disabilities remain active contributors to society. They reduce isolation, improve health outcomes, and strengthen the social fabric of our neighborhoods.

Investing in these programs is an investment in the values of equity and respect. When older adults and people with disabilities are supported to live, work, and thrive in their communities, everyone benefits. Families experience less strain, local economies grow, and communities become more compassionate and resilient.

It is important to recognize that adults with intellectual and developmental disabilities (I/DD) are living longer than ever before. Advances in medical treatment, improved living conditions, strong caregiver supports, and the growth of autonomy and self-advocacy efforts have all contributed to this increased longevity. As a result, the need for continued and expanded community-based programs for older adults will be critical for years to come. These programs must evolve to meet the unique needs of aging individuals with I/DD, ensuring they can thrive with dignity and independence throughout their lifespan.

I urge the Committee to continue championing policies and funding that sustain and expand these vital programs. By doing so, you affirm the principle that every individual—regardless of age or ability—deserves the opportunity to participate fully in community life.

Thank you for your leadership and for collecting these stories and statements. I am grateful for your commitment to ensuring that our nation remains a place where all people can live with dignity and purpose.

Brittany Goodrich

Brittany Goodrich

Director
The Kennedy Willis Center on Down Syndrome

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from North Carolina

Liz Saylor, Raleigh, North Carolina

Dear Members of the Special Committee on Aging,

Community living matters for All, keeping people Home, Healthy and Respected, Thank you All! Love and Care!! ♥♥♥

David Hollingsworth, Fayetteville, North Carolina

Dear Members of the Special Committee on Aging,

Community living matters to me because it represents connection, strength, and resilience during times of struggle and uncertainty.

Mother and I receive Medicaid and we definitely need basically for survival. Without it, we might not make it.

Ray Hemachandra, Arden, North Carolina

Dear Members of the Special Committee on Aging,

Hundreds of thousands of Americans with significant intellectual and developmental disabilities are on waitlists for services, often more than a decade long. They either lack support services entirely or only have them partially, inadequately, and ineffectively.

These precious intellectually disabled Americans are part of every demographic population, including every racial and ethnic group. They are white, Black, Latino/Hispanic, Asian, Indigenous, Middle Eastern, biracial, and multiracial—every such identity designation. They live in every geographic region, every state, and every local community. They are born in families of every socioeconomic class and every partisan political group, including Republicans, Democrats, and independents.

There is no group of Americans more vulnerable and at risk than those with significant intellectual and developmental disabilities.

When we fail these intellectually disabled Americans, they do not receive proper care. They frequently fall into crisis. They become ill. They become homeless—they make up a disproportionate part of our homeless population. They are victims of sexual violence and sexual abuse at truly unfathomable rates. They become substance dependent. They die prematurely, and perhaps even worse live awful lives of desperation, marginalization, and genuine suffering—not

because of their disability but because of our deficits of care, connection, and inclusion.

These are real Americans living far too poorly and dying far too early.

But we almost never talk about them. Americans with significant intellectual and developmental disabilities are not important enough for us to talk about them.

The waitlists also mean that many Americans with intellectual and developmental disabilities lack needed support throughout their entire childhoods, when certain therapeutic services might be most effective and impactful and have the potential to change the course of their lives for the better.

My child's life tells the story of what can happen when supports and services are made available. It's not a perfect story, of course, but it's a good story.

Nicholas has had a Medicaid waiver specific to North Carolina—initially called a CAP waiver and now called an Innovations Waiver—since January 2010, when he was 9 years old. Nicholas is autistic and intellectually disabled, with co-diagnoses of severe mixed expressive-receptive communication disorder, obsessive-compulsive disorder, sensory integration disorder, socialization delay and impairment, and tic disorder. When he received the Medicaid waiver, he was prone to tantrums and self-harm. He also has a physical disability with severe ulcerative pancolitis. When that onset in 2016, Nicholas lost 25-30 pounds and was hospitalized for a month—he now receives medication infusions for several hours at an infusion center every eight weeks.

Now 25, Nicholas has a good life. He volunteers every week both at MANNA FoodBank and at Asheville Buncombe Community Christian Ministry. He works a few hours each week at a paid job at an ice cream shop, Annie B's Homemade Ice Cream, that has extra support for its workers with disabilities. He has social connections through community groups and therapeutic recreation programs. He swims and shoots hoops at the Y. He goes to camp some summers. He likes to go on walks and hikes, and he's an impressive juggler. He has a girlfriend, who also is autistic and intellectually disabled.

Nicholas can never live independently without support. But he is not in an institution, and he is a vibrant, valued, and contributing member of his community. So much of his life is possible because of the services he receives, in combination with a community support circle and, well, me. He has a support worker for several hours each weekday right now—even with the Direct Care Worker workforce crisis—and that helps anchor his well-being and community participation.

Without the Innovations Waiver he received at 9 years old, I truly believe—I know—most of this would not have been possible. I want the possibility of such lives for all our children and adults with significant intellectual and developmental disabilities.

Surely, we all support far better circumstances for Americans with intellectual and developmental disabilities. We want to support families and one another and help take care of our children and adults with significant IDD.

That's the stand we have to make, every day, every one of us: No more generations of hundreds of thousands of Americans with IDD living and dying in desperation.

Urgently, we must end all the waitlists for services and community inclusion for Americans with significant intellectual and developmental disabilities—to improve the lives, well-being, and health of every at-risk and marginalized intellectually and developmentally disabled person, because they are an essential part of us.

Surely, at last, we know: They *are* us.

Donna Austin, Greensboro, North Carolina

Dear Members of the Special Committee on Aging,

Community living matters to me because my adult son depends on these services in order to live in the community. My son is non verbal, has severe autism, significant intellectual disability, epilepsy, and chronic gastrointestinal issues. My husband and I are senior citizens, and we would not be able to care for our son with out help because he requires 24/7 care. I fear for my son's future, especially as our services are in danger of being cut. Please don't cut the services that our loved ones need!

Ruth Singerstrunck, Monroe, North Carolina

Dear Members of the Special Committee on Aging,

Community living matters to me because https://youtu.be/jeOf2n9ZO2M. Here is our story from a few years ago on the today's show.

Marie Corwin, Chapell Hill, North Carolina

Dear Members of the Special Committee on Aging,

Community living matters to me because my son deserves to feel like a productive member of society. He works for the ITS dept at UNC 12 hours a week, 11 mo a year, since he graduated HS in 2017 (not counting 2 yr layoff for pandemic). He enters data into software that is being tested. It's a repetitive, tedious job and he excels at it. So he is a valued employee. But UNC will not hire him without a job coach 4 hours a month. Having autism his social, analytical, and communication skills can cause misunderstandings between him and his superiors. This occurs when it comes to annual re-employment, training on new software, etc. Medicaid pays for this up to 4 hours a month of job coach time. It allows him to get up and get on the public bus every morning (with other neighborhood commuters) to go to an office desk where he is part of a team and appreciated for his unique skills. He collects a small paycheck which supplements his SSDI. This is the only service he gets.

Eileen Juric, Raleigh, North Carolina

Dear Members of the Special Committee on Aging,

Community living matters to me because it’s important!

Randy Jones, Fayetteville, North Carolina

Dear Members of the Special Committee on Aging,

Community living matters to me because we have to live and respect each neighbor as you would expect to be.

Marjory Moore, Shelby, North Carolina

Dear Members of the Special Committee on Aging,

Community living matters to me because my youngest son is severely & profoundly Autistic & non verbal. If he were not getting professional community inclusion services, he would never leave his AFL home & would not get to experience the world in a way that is "normal" for everyone else. My son deserves to go shopping, dine out, see a movie, go to the park, hike trails, catch a fish, see waterfalls & all of the wonders of nature he cannot view from his window. Without these services, my son may as well be a prisoner in his home which is completely unfair to a young man who has never done anything wrong in his life. He has already exceeded the lifespan for persons with his particular disabilities. We do not know how much time he has left... please allow him the freedom to enjoy that time. Thank you.

Crystal Boyce, Spring Lake, North Carolina

Dear Members of the Special Committee on Aging,

Community living matters to me because without it my son couldn't have direct care workers to provide my mother, who has been my caregiver for 25 years a break and down time. My son is wheelchair bound, has Epilepsy, blind and 100% care for all ADLs. People like my son need these programs to thrive and survive.

Paula Poe, Hillsborough, North Carolina

Dear Members of the Special Committee on Aging,

Community living matters to me because I recently cared for my partner of 29 years at home as he had vascular dementia and was unable to stay home alone after a certain point in his illness. I was retired and worked only 2 mornings a week and had to have someone with him those mornings. His family was not present for his care unfortunately. Careyaya.org stepped in and helped me with a referral from Duke Family Care Services. Without community care, I dont know what I would have done without referrals from care groups and my Careyaya. We have very little money and are both on Medicare. The nurses who came were from Medicare were lifesavers I will say. They prepared me for everything that happens with dementia/alzhiemer's patients and for the end of life progression. I had to leave my job when his disease progressed as I could not afford full-time care for him. His life ended peacefully but it was very hard on me. The Hospice people allowed me to bring him to a facility for 5 days to give me a rest which I very much needed. He died not long after his Hospice stay in August of 2024. Shortly thereafter at Thanksgiving, I had a stroke and was unable to care for myself. Luckily, I have a son nearby and stayed with him until I felt stronger. Without community support, we would not have been able to be at home with our loved one. Thank you for helping us.

Deborah DeWeese, High Point, North Carolina

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a 71 year old woman who has been in a wheelchair since 1996. I became disabled because of steroids for my asthma which caused vascular necrosis in all my main joints and I couldn't walk anymore. I have been disabled and independent every since then except for last year when I had to leave the house my husband and I had bought because of domestic violence. I went into a group home then and it was terrible with people yelling at me and bossing me around. I have also gone into nursing homes a few

times after surgery and hated the idea of living there too. I am a very independent person and I take care of myself. I have a lady come in 3 hours a hours a day to help me and I don't know what I would do without her help. I also don't know what I would do without my Medicaid help. I need my health care and benefits and my card
Plus I am under a Medicaid program that helps me in the afternoons. They pay 3/4 of my rent. They basically help me keep my mental health. If I loose all this I don't know what I will do, possibly suicide before I move in with my daughter in law.

Sarah Hamaker, Asheville, North Carolina

Dear Members of the Special Committee on Aging,

I have worked as an in home caregiver CNA for 21 years. Many of my clients are with Medicaid. Many have no other help and are barely making it. After April 2010 we were no longer allowed to go out once a week for Medicaid clients to get groceries or prescriptions. I was worried about them going without food or medicine and wrote many officials at the time, but to no avail. No one even acknowledged my letters. I did have clients who went without medicine and food at times because no one was available to pick it up for them and we were no longer allowed. These people are desperate for care. Many are alone . If they have family, often they are just as old and sick as they are. Many try to put on an act that they are not as sick as they are because they fear being put into a nursing home and the era they were raised in was one where you were not supposed to admit your struggles.
The people I work with are struggling just to pay the bills each month and still be able to get groceries and medication. Some are just over the Medicaid limit and are struggling to pay their medical insurance (that must cover their many complex issues) on top of it all.
They wonder how they will get through the month. Then they have unexpected house repairs that must be done on top of it all.
The elder population deserves our respect, care and concern, not to be cast aside as if they will somehow be magically provided for by???
Who are we expecting? These people worked hard and paid into the system. One lady had a tragic work injury permanently disable her and take from her the profession she loved. The majority of these people are not lazy. Go through and find people who truly are abusing the system and hurting these who need it, but don't take it out on these people who worked hard and proud, depending on us to be there for them now.
Thank you
Sarah Hamaker, CNA

Timothy Rushing, Monroe, North Carolina

Dear Members of the Special Committee on Aging,

People with disabilities matter.

John D. Dodd, Morganton, North Carolina

Dear Members of the Special Committee on Aging,

I live in sec8 apartment complex I've Never lived in one before I have to say I Would never live in one again because Of the hate and nosiness over my Medical issues!

Erika Yucius, North Carolina

Dear Members of the Special Committee on Aging,

Community living matters to me because we need to value people at all ages.

Michael Burnham, Greensboro, North Carolina

Dear Members of the Special Committee on Aging,

Community living matters to me because I am 72 year 72-year-old male and I need to stay safely in my large rental complex of The Park at Midtown, off of W. Friendly Ave, Greensboro, NC 27410. It is very convenient for grocery shopping, my doctor's appointments, and other types of shopping at The Friendly Center in Greensboro, NC. So please ensure that I may live another 10 years of safe life in my Greensboro, NC, Apartment Complex.

Ashleigh Swayze, Hendersonville, North Carolina

Dear Members of the Special Committee on Aging,

Community living matters to me because my son is a recipient of CAP/C - a Medicaid HCBS program that supports children with disabilities. With this assistance, my son has a fantastic case manager who can connect us to resources, and my son has a direct support professional who he adores that can take him out in the community. CAP/C has provided us with an adaptable car seat for my son, who is 10 and still needs a 5-point harness, and an adaptable bike so he can ride a bike like his typical peers. Medicaid HCBS programs quietly provide a TREMENDOUS support to families like mine. Without this support, our son and our family would suffer. He would lack the necessary support we couldn't afford otherwise, and we may have to lessen our hours at work just to care for him. HCBS programs make for a better community - the whole

family is supported, so we can support others, we can hold employment, and we can remain physically and emotionally healthy. I hope you continue to support these INVALUABLE programs,

---

Liz Saylor, Raleigh, North Carolina

Dear Members of the Special Committee on Aging,

Community living matters to All, assisting those of us with lower incomes keep Dignity, Care, Compassion and Respect! Thank you All! Love Guides and Rules All!!! ♡♡♡

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Ohio

Bianca Tropeano, Urbana, Ohio,

Dear Members of the Special Committee on Aging,

Community living matters to me because it does

Diane Jonel, Maple Heights, Ohio

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows my special needs daughter the opportunity to be included in her community activities, work force activities and community inclusion as a whole. Through the supports provided under Medicaid HCBS benefits she has had the opportunity to personally engage with many people through out various communities that know her when they see her and she has developed a personal rapport with many of them. She has developed employment skills through the SAW program funded by Medicaid HCBS. She feels apart of she community and it provides her with a sense of inclusion. Although, she has special needs, she is still connected and accepted as a citizen just like everybody else. She had developed her own sense of independence and knows that she has rights just like everybody else does. Without the supports of Medicaid HCBS this would not be possible for her.

Jill Chapin, Cincinnati, Ohio

Dear Members of the Special Committee on Aging,

Community living matters to me because it will continue to make a huge impact to a good percentage of our population! I have worked over 20 years with aging individuals and individuals with disabilities. I have seen how programs such as job coaches, employment services, personal assistance, transportation, respite care has changed lives! Not only the lives of individuals with disabilities, but those who care for them, family and friends, a ripple effect that affects the entire community! These are essential programs to be supported. Without these programs, we can face a real risk of unnecessary institutionalization which will diminish their quality of life, and also increase costs.

It all around, supports a healthy community being able to live on their own in the community, to work and maintain a job to enjoy hobbies And be close to family and friends for support.

Prioritizing the services ensures that people with disabilities have choices in all aspects of life and can thrive an integrated settings!

Thank you! I believe this is important! I'm grateful for the opportunity to write this letter and to share my thoughts and passion and heart for the lives of many people I love!

Sincerely!

Tonya Fisher, Kettering, Ohio

Dear Members of the Special Committee on Aging,

Medicaid HSBC Community living matters to me because my son with Down Syndrome, Sensory Processing Disorder, Autism, Type 1 Diabetic, (Severe pancreatic deficiency) and fed through feeding tube. Disability Providers, Case Workers and Community Based Services are so very important for my Son and 100's of thousands of other people with Disabilities. They are citizens of our United States, born here and have meaningful lives that truly matter in our Country. Home based help matters greatly as this helps them a lot and their Caregivers to help those with needs succeed. Help at home, schools, Community work, help them to be more independent and thriving people. This is very important to all of these families. Critical. Thank you for hearing our own life story. Please, Please, Please continue the help for those that especially need it. They deserve this and this should never be an option! Ever!

Amy Smith, Canfield, Ohio

Dear Members of the Special Committee on Aging,

Community living matters to my son, who is 29 years old nonverbal with severe autism, I am my son's paid caretaker by the state my son is on the Ohio shared living waiver, I have been taking care of my son at diagnosis at 2 years old since Dad and I divorced, Daddy went on with his life autism free as he is now still, I gave up my entire life to take care of my son at diagnosis and we only lived on his social security and his child support from his father dad has not helped out since our divorce with my son, I wasn't able to work all those years because I had to care for my son I had to quit my job, he finally got approved for the Ohio share living waiver 5 years ago if my son would lose this waiver my son and I would be homeless in the streets, we have no family to take us in my parents are dead, my son's father currently wants nothing to do with his son he doesn't care about his son he doesn't help me get any breaks from his son breaks from caregiving, he lies to my son and says he'll come see him my son waits for him he's a no-show his birthday was September 13th dad lied to him and said he'll meet him at the mall he was a no-show my son cried that day ,he did nothing for my son's birthday is doing nothing for him for Christmas we cut that out of our life due to the way he treats my son, my son is my best friend my son is my best buddy I love him and I will take care of my son till I'm old and gray I don't want my son to lose his waiver and him being homeless, having his waiver means everything to him he lives

with his family, he goes out in the community and does activities that he enjoys like going to the mall, bowling going to the library, going to the laundromat, going grocery shopping he enjoys being in the community and doing activities with Mom. Im his whole world he knows I take care of him and love him and he knows his dad is not here and doesn't care for him. At 50 years old I'm still dedicated to taking care of my son that he is first before myself as he always been, he didn't ask to have autism he did not ask for autism to Rob his voice and Rob his entire life, my son needs 24-hour care 24-hour supervision he cannot be left alone he's been nonverbal since 2, please continue to fight for our disabled population fight for our waivers fight for our children and adults with disabilities to stay in their communities please thank you.

Rochell Stufflebeam, Springfield, Ohio

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter matters. She attends a Day Program at a community animal welfare league. She is able to learn daily living skills, have friends, be part of the community and help care for the animals until they are adopted. She is a valuable member of the community. I want everyone to see her and not the dollar sign behind her care. She is healthy and thriving because she has support. A parent can only do so much and we will not live forever. We need her support and services to continue.

Amanda Fontana, New Philadelphia, Ohio

Dear Members of the Special Committee on Aging,

Community living matters to our family because without it, we would either go back to living in extreme poverty or my adult daughter with disabilities would have to live in a group home without access to a sign language interpreter leaving her unable to communicate with those who would be caring for her. My daughter's HCBS allows her to live at home with me (her mother) and her siblings. My daughter has severe developmental disabilities and is Deaf. In order to communicate she relies on American Sign Language. Meaning, those caring for her need to be fluent in ASL or she requires an ASL interpreter. HCBS allowed me to become a certified provider through the Ohio Department of Developmental Disabilities so that I could provide services in the home for her activities of daily living. I am also the only certified provider in our county that is also certified in American Sign Language. HCBS also allows for my daughter to access an adult day program, community inclusion activities and more because HCBS provides access to an interpreter for her. If cuts are made to HCBS, my daughter would lose access to those services. She would lose access to her program because there would be no access to an interpreter and additionally, being her provider allows me to generate an income for the care I provide for her. Because she is 24 hour care, I am unable to work outside the home fulltime to

sustain meaningful income. If HBCS were cut, my ability to generate an income would live us in the position of like I previously mentioned, going back into extreme poverty, or my daughter having to be placed in a group home so that I could work outside of the home. But keep in mind the cuts in HBCS would mean no access to an interpreter in a group home. Cuts to HBCS would mean either extreme poverty, or a life without dignified care or being able to communicate with anyone, leaving no access to the community at all for my daughter. HBCS allows my daughter to be with her family and friends, allows her to access her community, it allows her to live a life where her civil rights are fully intact. Home and Community Based Services are our families lifeline to being a part of our community. It would be devastating to lose access to these services for our entire family.

Randi Renninger, Cincinnati, Ohio

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. HCBS help make this possible by helping people stay in their homes, attend school, work, take needed medications, get to see their much needed doctors, get the services they need and participate fully in their communities.

Mark Mendoza, Cincinnati, Ohio

Dear Members of the Special Committee on Aging,

Community living matters to me because my family's health and financial security depends on it.

Kofi Akwete, Fairfield, Ohio

Dear Members of the Special Committee on Aging,

Community living matters to me because these individuals needs a good home to live and enjoy life in a peaceful environment . I see the joy in their faces when they say they are going home to their own places of their own place . They feel independent and happy to tackle problems if any on their own .

Colleen Lee, Cleves, Ohio

Dear Members of the Special Committee on Aging,

Community living matters to me because the conditions of assisted living facilities are dreadful. I

visited a site that had a floor in the building known as the death floor. I've been disabled since 2009 and continued to work until 9/2019 when my health started to significantly decline. Moving into senior housing will provide people to check in on me on a regular basis and allow me to have quality of life that I wouldn't receive in assisted living. I can afford to live in senior housing ... not in assisted living that takes every dime you have and allots only $50.00 for toiletries, laundry supplies, and small food purchases. It is far more cost effective to help people in their homes than in a facility.

Thanks so much for reading my message and have a lovely day.

Jason McMahon, Springdale, Ohio

Dear Members of the Special Committee on Aging,

Community living matters to me because it is at this level that my direct interaction takes place.

Roberta Farinet, Dayton, Ohio

Dear Members of the Special Committee on Aging,

I live in a retirement community. WE have a complete array of service/needs. It ranges from independent, assisted living, medical care needed, Early dementia (can do personal care) and serious dementia (need complete care). I am independent, but friends need medical assistance and my husband was completely dependent dementia. Without the financial assistance of Medicare we would have lost everything - not just our house. Too many seniors need assistance - only heartless idiots would cut the lifeline that Medicare/Medicaid provide

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Rosemary Kohnen, Carthagena, Ohio Dear Members of the Special Committee on Aging,

Community living matters to me because my grown son Dan has autism. Dan has used/is using HCBS for supported employment, non-medical transportation, and case management. Dan worked in an enclave that was specifically for individuals with Developmental Disabilities, in the community. Dan needs non-medical transportation to go to the grocery store, arts group meetings, to go to the doctor/dentist, see his counselor, etc. Dan has case management, an SSA, through the Board of DD. He has a Level 1 Waiver. He attends ADS M-Th. Dan lives in an ARC house. Unfortunately, I do not own a car, and cannot give Dan rides. Dan needs his non-medical transportation in the community to get what he needs like food, clothing, OTC. Dan's SSA writes his ISP, which makes sure that all Dan's services and supports are on the same page. Dan also uses a Payee at the Board of DD, especially since his dad is in the nursing home with no

discharge date. I am disabled. That makes the services and supports that Dan gets with HCBS all the more critical. Thank-you. God Bless!

Ashley Thompson, Groesbeck, Ohio

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a person with a disability living in the community. I enjoy to go out in the community every day and ride the public transportation and engage with others in the community people often with disabilities also. I also enjoy to engage in talks with the veterans in the community many often say that I am a good listener and a good person to talk to. That is just some of many reasons why community living matters to me

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Vicki Larson, North Olmstead, Ohio

Dear Members of the Special Committee on Aging,

Community living matters to me because this allows my son Tristan, who is 25 and has severe autism, to attend a day program and participate in weekend sleep away camps.

Medicaid funds not only pay for these essential activities which improve his quality of life but also pays for the transportation to these programs.

Medicaid also pays for independent providers who can care for him at home so he does not end up in a group home or a residential facility.

Beverly O'Hara, Cleveland, Ohio

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities deserve to live with as much independence and dignity as possible. My family branch has 3 individuals with various handicaps. When I was younger I worked in a care facility for adults 18 & over with various mental and physical handicaps that made it impossible for home care at that time. With HCBS Medicaid they can now remain at home as part of the family and be a part of community activities. These are the nicest, sweetest people you would ever want to know. The fact their families can rest easy that their loved ones can be cared for at home means everything to them. Please do not disrupt funding for such a worthy effort.

Emily Billings, Columbus, Ohio

Dear Members of the Special Committee on Aging,

Community living matters to me because my son deserves to be a part of our larger community with his brothers.

Charles Tribett, Toledo, Ohio

Dear Members of the Special Committee on Aging,

Programs like Medicaid Home and Community-Based Services (HCBS) have a profound impact on our family's life. These supports are essential for my son, who has non verbal autism, and my brother, who has Down syndrome. HCBS is not just a program for them — it is what allows them to live with independence, dignity, and real connection to their community.

Because of HCBS, my son and brother are able to stay in their home, participate in daily life, learn, grow, and be surrounded by the people who love and understand them. These services help them attend school, work toward their goals, build relationships, and be active members of the community — not isolated or placed in an institution.

Life in the community matters to us because it gives my son and brother the chance to be themselves, to be included, and to be valued. Being part of everyday life allows them to develop skills, make friends, feel safe, and experience joy and belonging. It lets them contribute to our community in their own meaningful ways.

Without Medicaid HCBS, our world would look drastically different. My son and brother would lose the supports that keep them safe, engaged, and able to thrive at home. They would lose the opportunity to live the full, connected lives they deserve. These services are not optional — they are lifelines.

People with disabilities deserve the same opportunity for independence, dignity, and community as anyone else. Our family's experience shows why HCBS is essential and why life in the community must be protected.

I hope our story helps Congress understand what is truly at stake and why programs like Medicaid HCBS make a real and life-changing difference for families like ours.

Brennan Kinch, Fairfield, Ohio

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a completely blind homeowner who works 8 to 12 hours a week and needs to be able to get out of his house in order to interact and have fun in the community and without Medicaid resources such as this and other programs I would be stuck inside my house, isolated and unable to get out to access the resources that I need to access in order to live a good quality of life unlike my sided peers who are able to get out without any problems

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Karen Smith, Eastlake, Ohio

Dear Members of the Special Committee on Aging,

Community living matters to me.

Melody Holloway, Columbus, Ohio

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a totally blind 40 year-old woman with additional disabilities, including autism level, one with no intellectual disability, ADHD, complex posttraumatic stress with dissociation, EHLERSDANLOS disease, non—24 hour sleep WAKE disorder, fibromyalgia, chronic fatigue, long-term damaging effects of bacterial pneumonia, Covid, psychotropic, medication, overuse, chemical/pesticide, exposure, hypoxia, acquired hearing damage, processing trouble, debilitating migraines with several hits to my head, seizures, etc. I am someone you would think would need come home and community based services however I was in fact a care provider. I was on both sides. It's assumed that I would have staff in my home. I know many others who need someone to take them to the store, help them pick out groceries, do their laundry, clean their homes, accompany them to medical appointments, bathe dress, and feed them, accompany them to work, lift them if they fall, etc. This in fact does not apply to me however, many other others do you need the services. I live with a dual Medicare Medicaid plan, supplemental security, income, benefits, and a rent subsidy that do not allow me to marry, have a child, adopt, foster, earned enough to file an IRS 1099 form, open the animal rescue/long-term care facility I'd always hope to. I had cared for my dearest friend who had traumatic brain injury. She passed away over four years ago because of perception of both of us. Her family assumed that I would need HC services when I was trying to become certified to care for her. I have apps that provide visual and auditory interpretation on my phone, devices that can read cash, etc., screen readers that speak text on computers and mobile device devices, GPS applications, which help us find directions to destinations, text to speech, color, identification, etc. I perform most tasks by feel. We also have durable medical equipment that talks to monitor

bodily signs and refreshable braille displays with electronic pins that move we can write, edit, word process, as well as pair Bluetooth to smart phones, computers, and other mobile devices. This is why I do not require home and community base services. I aspire to become a certified 24 hour in-home caregiver however have received backlash because I am multiply disabled. I cannot prove the experience I've had doing this since before I was 16 years old. HC services are very important however funding to pay for the previous mentioned devices as well as the application purchases and subscriptions that we use which use our phones camera or a human volunteer or trained agent to look through a camera to provide any aspect of visual interpretation, such as reading restaurant, menus, print documents, medication, information, cooking instructions, recipes, mail, personal medical and financial paperwork, photo IDs, insurance cards, etc., then typing up this information. Emailing it to us, checking TV guides for us, helping a shop online, etc.. We also need the coverage for these services that could be considered blindness specific. Doctors do not know what these applications and technologies are therefore they're not signing off on them. Medicaid has got to cover these applications and devices as well as the durable medical equipment that is accessible to us so we're not having people do for us. We fight too hard to pay for these technologies. I as a an aspiring home and community based services provider yes living with several disabilities and occurring health conditions and full support of the advancement of HC services. There is a shortage and if people were not assumed in capable just because of condition and external appearance without anyone dropping the assumption that we Cannot when they don't know what these disabilities actually are, many of us could actually become care providers.

Daniel Scullion, Alliance, Ohio

Dear Members of the Special Committee on Aging,

IT'S. OUR RIGHTS TO AND OUR CONSTUTIONAL RIGHTS SO STOP TRYING TO TAKE IT AWAY FROM US .....AMEN

Melanie Marquise, Wapakoneta, Ohio

Dear Members of the Special Committee on Aging,

Community living matters to my son, because it allows him to have friends, go places and decide what he wants to do, like going out to restaurants, movies and other fun places. He can live in his own house, decide what he wants to eat and what he wears. If he were in a nursing home most of the things I mentioned would not be available.

Gerald Young, Cincinnati, Ohio

Dear Members of the Special Committee on Aging,

Community living matters to me because. For more than 10 years I cared for a quadriplegic. I know and understand their emotional and physical needs. They deserve the same respect as any person who can walk or go about their daily lives.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Oklahoma

Written Statement for the Record

Allie Williams, Cure SMA Supporter
Stillwater, Oklahoma

for the

U.S. Senate Aging Committee Hearing
on Medicaid Home and Community-based Services

My name is Allie Williams. I am a long-time resident of Stillwater, Oklahoma, a small town in north-central Oklahoma. I am an active community member. I perform with the Stillwater Community Singers—a local choir—and I play Dungeons and Dragon at a nearby gaming shop. You may also find me in a city park near my home during my daily walk. I serve on a national advisory council for a nonprofit organization, and I help raise awareness and mentor young people in disability rights.

None of this would be possible without access to Medicaid caregiving services.

That's because I am also a person living with a rare condition called spinal muscular atrophy or SMA. SMA is a neuromuscular disease that severely weakens muscles needed for everyday activities such as breathing, eating, crawling, and walking.

When I was born in 1981, my mom knew almost immediately that something was wrong. I was delayed in sitting up, rolling over, and crawling, and I missed other key milestones such as standing, walking, and sitting independently. I was diagnosed with SMA at age 18 months old. At age 4, I received my first wheelchair—a manual chair. I transitioned to a motorized scooter at age 8, and then to a power wheelchair, which I have relied on since I was 13.

When I lived at home, my family helped me get in and out of bed, transfer to my wheelchair, and manage daily activities, including meal preparation and bathroom support. But when I left home after high school to attend college, I began using paid caregivers funded through Medicaid. At first, I was approved for only 12 hours of caregiving a week—just enough for someone to help me get up in the morning and into bed at night. I depended on my college roommate and friends to help me throughout the day.

As my condition progressed, my Medicaid caregiving hours increased. Until recently, Oklahoma Medicaid approved 47 hours of care a week. This included Advanced Supportive/Restorative (ASR) hours, or what I refer to as transfer hours, during which my caregiver uses a Hoyer lift to safely transfer me in and out of my wheelchair in the mornings, at night, and for bathroom use and other essential activities. My caregivers also assist with personal care and prepare meals and snacks that my stomach can tolerate due to my gastroparesis.

I quite literally could not do anything without my caregivers.



But simply listing tasks minimizes what caregivers, and caregiving hours, truly mean to my health, independence, and dignity. My caregiving hours nourish me physically, emotionally, and socially. Just being able to get up in the morning, wash my hair, put on makeup, brush my teeth, and pick out a cute outfit for the day helps me feel human. My caregiver gives me the opportunity to feel good about myself and allows me to be independent and pursue what I need and want to do each day and each week.

My life, health, and independence depend on caregivers. And caregivers are only possible through Medicaid.

Many people with disabilities and older adults fear what policy changes or funding cuts could mean for their access to Medicaid caregiving. Unfortunately, this fear is my reality. My state is proposing to reduce my caregiving hours from 47 hours a week to only 38. This reduction includes cutting the specialized ASR hours that allow me to safely transfer in and out of my wheelchair to use the bathroom or participate in community activities. If this cut goes through, my bodily autonomy and community engagement will be jeopardized. Instead of using the bathroom when I need to, like most people do, I would be limited to once in the morning, once during the day, and once at night.

I am appealing, but if the cut stands, it will have devastating effects on my life. I have already had to limit my community activities because of my current level of support. If my caregiving hours are reduced, the first thing I would lose is choir practice, something I look forward to every week. The holiday concert, which fills my spirit, would also have to go. The caregiving cuts would leave me isolated at home and could endanger my health, as I would be forced to limit my food and liquid intake to unhealthy levels due to bathroom limitations.

This ordeal has been overwhelming. It makes me want to scream or cry, because this is my life. I am an active adult, but because of my SMA, I need a caregiver for nearly every aspect of daily living. That is how essential Medicaid home and community-based services are. It is not just a program or a line-item, it is a lifeline.

I hope my personal experience is helpful as you consider ways to ensure that people with disabilities and older adults can access the caregiving services and supports they need to live productive and independent lives. I urge Congress to make life better, not harder, for people with disabilities and older adults by strengthening Medicaid and the vital services it provides.

Thank you for considering my views.

Cletara Mitchell, Madill, Oklahoma

Dear Members of the Special Committee on Aging,

Community living matters to me because my husband passed away and I could no longer stay in my house. Medicaid has helped me be able to live in senior housing because I have a provider comes 3 days a week. She does my shopping and pays my bills. Then she does my laundry folds and hangs up. She does my dishes each time. Then she cleans my apartment bathroom, bedroom, living room. She sweeps, mops and dusts. Without the service I have Noone to help me. I would end up in the nursing home which is under staffed. I still have my independence. Please don't cut. There are a lot more people out here that need this help then are cheating at it. Don't punish those of us that need this help.

Dale Bushyhead, Glenpool, Oklahoma

Dear Members of the Special Committee on Aging,

Community living matters to me because it's the right thing to do.

Traci Sutton, Oklahoma City, Oklahoma

Dear Members of the Special Committee on Aging,

Our identical twin daughters are 24 years old and receive waiver services due to the challenges they face from having Phelan McDermid Syndrome. This funding allows them to be part of the community, with direct care personnel supporting each of our daughters. They need this support to ensure safety, self-care, and social interaction. This program allows my husband and me to maintain full-time jobs as professionals. These services are vital to the mental and physical health of our entire family. It provides respite care, so my husband and I can take breaks. It widens the circle of caregivers who know our girls when we might not be available in an emergency. It improves the girls' mental health by providing opportunities to get out into the community and attend a day center. Check out SunhiveCollective.com to see some of the great things these funds support.

Please continue to fund these programs and consider giving additional funding to reduce the wait list for those who desperately need these services.

Paul Scott, Oklahoma City, Oklahoma

Dear Members of the Special Committee on Aging,

Community living matters to me because if we keep stepping on our selves then when we see that we are few in number, and then we won't have any one to speak for the rest of us, and we will be done on this Earth

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U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Oregon

Jennifer DiBello, Beaverton, Oregon

Dear Members of the Special Committee on Aging,

Community living matters to me because I want to able to live on my own some day.

Nathan Bucklalew, Oregon

To the Members of the Senate Special Committee on Aging,

My name is Nathan Buckalew, and I am the Co-Founder of Empowered Care, a small, family-operated disability support agency in Oregon. Long before I became a provider, I was simply a brother. I grew up supporting my sister, who has intellectual and developmental disabilities, and because of her, I saw up close how essential compassionate, stable, and person-centered support truly is. My sister shaped my entire understanding of what dignity, independence, and meaningful community inclusion should look like for every person with a disability.

Medicaid Home and Community-Based Services (HCBS) changed my family's life, and it is the reason I chose this career. HCBS allowed my sister to remain in our home, stay connected to her routines, attend school, and grow in ways that simply would not have been possible in a more restrictive setting. These services supported not only her—but all of us. HCBS gave my family the peace of mind that she was safe, supported, and able to live in the community she loved.

Because of what HCBS made possible for my sister, I built Empowered Care with the same values I learned as a sibling: respect, consistency, compassion, and true community inclusion. Today, we support individuals and families across multiple Oregon counties, many of whom rely entirely on Medicaid-funded services to remain in their homes and maintain their independence. We see firsthand how HCBS prevents unnecessary institutionalization, keeps families together, and creates opportunities for people to live full, connected lives.

If HCBS did not exist—or if funding or workforce shortages make services inaccessible—people with disabilities would face devastating consequences.
Without HCBS:

Many individuals would lose the ability to remain safely in their homes.

Families would be forced into impossible caregiving roles without support.

Parents would leave the workforce to care for their children.

Adults with disabilities would lose access to their communities, jobs, and education.

Provider agencies like mine would not be able to maintain a stable workforce or meet the growing need for services.

In short, HCBS is the difference between community and isolation, between independence and institutionalization. I have seen the impact as a family member, an advocate, and now as a service provider responsible for both the well-being of individuals and the workforce that supports them.

As someone whose entire purpose in this field started with caring for my sister, I cannot overstate the importance of HCBS for millions of families like mine. These services do not simply "help" people with disabilities—they uphold their rights, sustain their safety, and give them the chance to live the self-directed lives they deserve.

Thank you for taking the time to hear our stories and for recognizing the critical importance of home and community-based services. I urge Congress to protect and strengthen HCBS so that individuals with disabilities, their families, and the direct support workforce can continue to thrive.

Sincerely,
Nathan Buckalew

Nina French, Portoland, Oregon

Dear Members of the Special Committee on Aging,

Community living matters to me because you have SO DECIMATED WORKPLACE RIGHTS and people LOSE THE USE OF THEIR EDUCATION AND EXPERIENCE TO COVER UP FOR CRIME AND ABUSE

Debra Snipes, Corvallis, Oregon

Dear Members of the Special Committee on Aging,

Community living matters to me because I am unable to walk in a grocery store. My arm has been broken for more than two years and I cannot take a bath by myself.

John Anderson, Keizer, Oregon

Dear Members of the Special Committee on Aging,

Community living! Doesn't that imply everything anyone needs to know? We're all in this together and we need to support each other through these horrifically trying times.

Paula Jackman, Portland, Oregon

Dear Members of the Special Committee on Aging,

Community living matters to me because I am the Power of Attorney, Authorized Representative, and Representative Payee for a woman on disability who had 4 strokes and survived, and who still has cognitive limitations, aphasia, a contractured hand and arm, and difficulty walking. Prior to her strokes, she was a caregiver who was excellent at her work, and was able to work with difficult clients to help them accept care. She was able to go to an assisted living in 2021 and stay for 4 years during which she actually got rehabilitation which was not set up during the first 3 years after her strokes. She made great strides as the result of physical and occupational therapy, specialized medical care in many areas, and overall support to help her heal. She recently got into her own apartment and now has in-home care while living in the community. She would not have recovered to this point without long term care services to assist her in getting her basic care needs met because she has aphasia (cannot find words to express herself and has memory problems as well) and cannot articulate her needs or coordinate needed services. She still needs a home care worker to manage her cognitive deficits, as she does not notice what she has missed a lot of the time, she often cannot find words to request what she needs, and she has trouble reading and writing consistently and sufficiently to solve day to day problems. I only recently became her community advocate in 2022, and until 3 years ago, she has no one consistently who advocated for her. She gained these services when she went into assisted living, and she is now in need of a little less support as a result. This has helped her dignity tremendously. It also saves the system money to have her in an apartment getting less intense care. If she has not had Medicaid HCBS she would not been able to track her care needs, would not have been able to make appointments or get to them, would not have been able to explain what she needed to medical providers, and would not have gotten the care she received in order to improve her overall health. She would still be unable to read at all, she would not have corrective lenses in order to see, she would not have dentures, and she would still be depressed and unable to function. These services literally helped her turn the corner toward recovery and being able to do many more things independently. She still needs support to remain independent, and benefits markedly from these services so she can live in a way which allows her to have dignity and choice. She has been sad and devastated for years because of the inversion of roles from caregiver to the one receiving care; she benefited from the help she received most recently and made progress because of it. She is delighted to be living on her own and is rarely depressed now. She has the support she needs to manage her life and the

independence she wants in order to have self-respect and dignity. These services are vital for many. Please support them remaining funded and available to vulnerable people who would eventually either end up in more costly settings or who would become homeless and not survive for very long. Thank you for reading.

Steve Campbell, Florence, Oregon

Dear Members of the Special Committee on Aging,

Community living matters to me because working in education and vocational training with adults with disabilities taught me that independence is a learned behavior. That improves quality of life and cost of supports to taxpayers.

Joel Nista, Coquille, Oregon

Dear Members of the Special Committee on Aging,

Community living matters to me because I live in rural Oregon. I was born and raised in the city. Aging populations here seem to quietly get old and frail, silently dying in their homes not knowing the support avenues available to them due to lack of social interaction. Meals on Wheels and adult rehab is very much needed here. The cost of Medicare and Medigap plans are too expensive and poor coverage. We need Medicare for All.

Rosemary Schifferling, Forest Grove, Oregon

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter has had an intellectual disability since birth and is now 40 years old. Her significant disability prevents her from using transportation on her own, and due to her disability requires 1:1 support to all her appointments, assistance with scheduling and managing appointments and assistance with medication and she cannot get to doctors appointments without having a PSW (personal support worker) to assist. Also, without funding for Medicaid hours for groups she has no friends or group of her peers to associate with which would leave her stand alone. People with disabilities deserve to have these services in order to have any quality of life. Without them it would be just as bad as the old days when they locked them in institutions. Please understand how heartless and cruel this would be. Thank you.

Cindi Otis, Portland, Oregon

Dear Members of the Special Committee on Aging,

Community living matters to me because, I serve adults with developmental disabilities as a case worker. Most of them work, but cannot work full time, due to their advisability or that the type of jobs they have do not offer full time. They want to live on their own and can with some supports, but housing continues to be a challenge as they are priced out. If they did not have Medicaid they would not have health insurance, service providers to support them with living as independently as possible, and most likely end up on the street or die. They also could not move into a group home or foster care, as this is supported with their income and Medicaid. If Medicaid stopped then providers/family member will need to work elsewhere and the person will be lift alone and have no supports, some of them could die or get increased health problems, adding to the strain of the ER department.

Ty Young, Portland, Oregon

Dear Members of the Special Committee on Aging,

Community living matters to me because I am disabled myself and if it wasn't for partial Medicaid I wouldn't be able to have a power chair to get to my appointments and take my emotional support dog out and to be able to go to fun things. It would be hard for my wife to have to wheel me everywhere.

Juanita Rinas, Eugene, Oregon

Dear Members of the Special Committee on Aging,

Community living matters to me because it keeps people closer to their families, and loved ones, supports in their communities, where without suck programs, and support workers, these people would either end up in facilities, with no autonomy and quality of life, losing meaningful connections and purposeful activities that help them thrive. Many would end, sadly, houseless or on the streets in shelters without proper care or support.

Anna Cole, Bend, Oregon

Dear Members of the Special Committee on Aging,

Community living matters to me because not only am I physically disabled, I also have seizures. Living at home with my parents, who take care of me, but also schedule my medical appointments for me is a necessity. My mom is my personal support worker and she does a great job of making sure I am safe and cared for. Medicaid pays for my medications and the HCBS

pays my mom for the care she gives me. I get out in the community weekly with a paid support person as well. Their funding is so important! I spend my money in my community and am a productive citizen. Please keep funding Medicaid and HCBS. My life depends on it! Thank you.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Pennsylvania

DISABILITY RIGHTS PENNSYLVANIA

Disability Rights Pennsylvania
301 Chestnut Street, Suite 300
Harrisburg, PA 17101
1-800-692-7443 (Voice)
1-877-375-7139 (TDD)
www.disabilityrightspa.org

VIA EMAIL

December 8, 2025

Ranking Member Kirsten Gillibrand
Senate Special Committee on Aging
Attn: Grace Hart, Policy Advisor
628 Hart Senate Office Building
Washington, DC 20515

RE: Importance of HCBS, CILs, and Community Living for Older Adults & People with Disabilities

Dear Ranking Member Gillibrand and members of the Senate Special Committee on Aging:

Disability Rights Pennsylvania (DRP) appreciates the opportunity to submit this statement to the Senate Special Committee on Aging regarding the critical importance of supports that allow older adults and people with disabilities to remain in their own homes, stay connected to their communities, and avoid unnecessary institutionalization.

DRP is the federally mandated Protection & Advocacy (P&A) system for the Commonwealth of Pennsylvania. For more than 48 years, our agency has used its independent access authority to monitor facilities, investigate abuse and neglect, enforce disability rights laws, and advocate for person centered and integrated community services. In fiscal year 2024 alone, DRP responded to 4,817 service requests across Pennsylvania - including 2,067 cases involving HCBS, 2,216 involving neglect, 1,171 involving abuse, and 697 involving rights violations. Our work reflects the on-the-ground realities of Pennsylvanians who rely on HCBS to avoid institutionalization, maintain autonomy, and participate in their communities.

HCBS as a Civil Rights Safeguard: Through our individual and systemic advocacy, DRP has seen firsthand that HCBS is not merely a "service option". It is the primary mechanism that protects people from unnecessary institutionalization, fulfilling the promise of *Olmstead v. L.C.*

Our monitoring and casework demonstrate:

- Individuals with ID/A losing essential supports due to flawed needs reassessments that lowered needs without any change in condition; DRP's advocacy resulted in statewide reforms benefiting 37,844 participants in Pennsylvania's HCBS waivers.

- Older adults and people with disabilities are often disenrolled from long-term services despite continued clinical eligibility such as an individual with a Traumatic Brain Injury forced to reapply for services after an erroneous determination; DRP intervention has restored services without interruption.

- Adults stuck in nursing homes, psychiatric facilities, and carceral settings for weeks, months, or years longer than medically necessary because community supports were unavailable or underfunded.

The consistent pattern is clear: Where HCBS is strong, segregation decreases. Where HCBS is weak, Pennsylvania sees preventable institutional placements, rights violations, and serious risks to health and safety.

The Human Cost When HCBS Fails: From our 2024 Annual Report and ongoing casework, DRP has documented widespread systemic issues that harm older adults and people with disabilities when HCBS systems fail. Longstanding workforce shortages leave individuals without reliable aides, often going days without support for bathing, dressing, eating, or taking medication. Administrative and eligibility problems also routinely disrupt necessary services: people lose supports due to mistaken determinations that they are no longer clinically eligible, experience long delays in home modifications or assistive technology, and wait months for repairs to durable medical equipment needed for basic mobility or safety. These disruptions regularly lead to preventable hospitalizations, institutional placements, and increased Medicaid costs.

DRP's systemic work has also uncovered inaccessibility in community systems such as homeless shelters, transitional housing, and transportation, especially in Philadelphia, creating barriers that push individuals toward institutional settings. For those with mental health disabilities, inadequate community-based services often result in cycles of emergency room use, incarceration, or placement in locked psychiatric units. Our recent settlement with Chester County Prison illustrates the serious harm that occurs when community mental health supports are unavailable and individuals with serious mental illness are instead funneled into correctional settings.

What Strong HCBS Makes Possible: Across all our programs, DRP sees the life-changing impact of well-funded community living systems.

When HCBS systems function well, people with disabilities and older adults can live full and self-directed lives in their communities. Strong home-based supports allow people to remain safely in their homes, maintain autonomy, and avoid restrictive guardianships by relying on supported decision-making rather than unnecessary substitute decision-making. Effective HCBS programs make competitive integrated employment attainable by ensuring access to vocational rehabilitation, job supports, and transportation. They also ensure that people receive the assistive technology and durable medical equipment they need to communicate, move around safely, or perform daily tasks without institutional intervention. Vibrant community systems promote civic engagement by ensuring access to polling places and voting processes.

Perhaps most critically, **well-functioning HCBS and community systems reduce neglect and abuse by enabling independent oversight and by keeping people out of segregated settings where risks are higher and visibility is lower**. Strong HCBS is the backbone of community integration, personal autonomy, and equal opportunity.

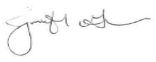
Federal Action Needed: To protect the rights of older adults and people with disabilities, Congress must prioritize stable, long-term federal investment in home and community-based services. States cannot sustain community living infrastructures with temporary or one-time funding initiatives. Federal action is also necessary to address the nationwide direct support workforce crisis, which undermines every aspect of HCBS delivery

by limiting availability, consistency, and safety. Strengthened federal oversight and clearer standards are needed to ensure that HCBS systems remain accessible, timely, and transparent. DRP collaborates closely with Centers for Independent Living, the Pennsylvania Developmental Disabilities Council, University Centers for Excellence in Developmental Disabilities, and community service providers across the state to advance community integration. These partnerships help ensure that services are delivered in the most integrated setting, and that Pennsylvanians with disabilities can fully participate in community life. However, these also remain significantly underfunded despite their central roles in community integration and civil rights enforcement. Additionally, expanded investment in community-based mental health services is critical to reducing inappropriate institutional or carceral placement of people with mental health disabilities. Together, these actions would help ensure that older adults and people with disabilities can live safely, independently, and with dignity in their own homes and communities.

Community inclusion is not only a policy goal- it is a right and a necessity. We urge Congress to make permanent, meaningful federal investments in HCBS, strengthen community living infrastructure, and support the civil rights protections that enable people to remain integrated in their homes and communities.

Please contact Dale Verchick, Director of Public Policy, at dverchick@disabilityrightspa.org with any questions.

Sincerely,



Jennifer Garman
Chief Executive Officer

Xiomara Rojas, Boothwyn, Pennsylvania

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows the caregivers to be able to participate and assist their love ones with the everyday care. When a caregiver participates or has their love one near them, there is such a piece of mind that comes with it; as you know that they are not lacking for any essential thing or being abused or mistreated. It costs much less to keep them at home or near you than in a group home or nursing home. We just want support and the waivers provide that.

Suzanne Lamborn, Nottingham, Pennsylvania

Dear Members of the Special Committee on Aging,

Community living matters to me because we all need to listen

Mary Judge, Scranton, Pennsylvania

Dear Members of the Special Committee on Aging,

Community living matters to me because the people in the community living situation deserve the fullest life they are capable of

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Joseph Vedam, Hatfield, Pennsylvania

Dear Members of the Special Committee on Aging,

Community living matters to me because as a parent of an individual with intellectual disability and Epilepsy, I understand how much difference the family living together and watching over my daughter can make. The community supports available to her make her happy every day.

R.S. Mountain Top, Pennsylvania

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities and older adults deserve to live with independence, dignity, and connection to their communities.

Kelly Powers-Zollers, Hatboro, Pennsylvania

Dear Members of the Special Committee on Aging,

Community living matters to me because my brother is 55 years old and he has special needs. We never thought he would be able to live independently, but through funding, he was able to move out of my parent's house and live on his own! My brother is a dishwasher. He works hard, but with the minimal pay he receives could not afford to live on his own. He does not collect SSI because he chooses to work, so the help he receives with his rent each month is a game changer! He is so proud that he can live on his own. I am his only sibling. My Dad died and my Mom is now in memory care. Without this help, I don't know where my brother could afford to live. His funding for the past 20 years through Community Options has changed the quality of his life and of our family's life. We couldn't be more grateful for this support and he needs it. How else would he survive if something happened to me and he was all alone? Community Options provides staff to take him to doctor appointments in addition to subsidizing his rent. I don't know what we would do without this support!! Please keep funding for housing! Older people with disabilities need your help.

Debra Wontor, Hawley, Pennsylvania

Dear Members of the Special Committee on Aging,

Community living matters to me because no one should be alone. Older people and people with disabilities depend on others for care and companionship. Their families rely on assitnace from others because it takes a lot of time and effort to care for the elderly and disabled.

Tamicka Grooms, Allentown, Pennsylvania

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows participants to feel included and gives them the opportunity to learn new life tools

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Richard Rothwell, Erdenheim, Pennsylvania

Dear Members of the Special Committee on Aging,

I am writing on behalf of my daughter, Colleen who is 44 years old and profoundly intellectually delayed. Medicaid HCBS has allowed her to attend an adult day program for the last 23 years. At her program she participated in community activities such as outings to libraries, parks, senior living centers, and volunteered at a pet shelter. She is also taught daily living skills, engaged in an exercise program as well as a therapeutic equine program.

Her program has allowed her to grow as a person and provided her a sense of accomplishment and improved her self esteem. Medicaid HCBS has helped her to become the happy, well balanced adult she is today despite her disabilities.
Thank you,
Richard Rothwell

Melissa Giannini, King of Prussia, Pennsylvania

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter is on Medicaid and it covers all her medications and therapies at school. It also covers her doctors visits. She has a heart condition and is autistic.

Hope Punnett, Philadelphia, Pennsylvania

Dear Members of the Special Committee on Aging,

Community living matters to me because at age 98 I am very involved in the life of my city and emotionally invested in my community, but I am homebound. HCBS helps make this possible by helping me to participate fully in communal life.

Richard Sommers, Allentown, Pennsylvania

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a daughter with disabilities

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Denise Mendoza, Aliquippa, Pennsylvania

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a daughter who has Down Syndrome. We thank God that there are programs that she can attend to get her out of the house so she can learn to be independent. To be able to depend on funding to help us pay for this service that we couldn't afford on our own. My husband and I are 67 years old and are retired. But we still have to work because our small home is not paid off. It should have been but we had to borrow against it for a new roof then windows and before you know it we owe another $45 thousand dollars. With the cost of groceries sky rocketing, gas, home and auto insurance as well as utilities we don't have anything left to help our daughter get out into community programs. We need this funding. We

need her Medicare and Medicaid. You people have the power to help all who are struggling and in need.
Respectfully, Denise a concerned parent who needs you!

Paul Harvan, Flourtown, Pennsylvania

Dear Members of the Special Committee on Aging,

Community living matters to me because my grandson is autistic and need support to function in the community.

Hiren Ardeshna, Collegeville, Pennsylvania

Dear Members of the Special Committee on Aging,

Community living matters to me because this is the most important thing that will keep children from being institutionalized. Histroy has already proved that institutionalization does not work

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Dumitru Neagu, Philadelphia, Pennsylvania

Dear Members of the Special Committee on Aging,

People with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. Programs like Medicaid home and community-based services (HCBS) help make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.

Regina Brooks, Pittsburgh, Pennsylvania

Dear Members of the Special Committee on Aging,

Community living matters to me because it promotes well being for all.

Tina Roberts, Clarendon, Pennsylvania

Dear Members of the Special Committee on Aging,

Medicaid Home & Community Based Services matters to my family because both my spouse & I are disabled Americans with my spouse recently being of retirement age. We are just now learning about & utilizing Home & Community Based Services to navigate Health,

Transportation, Home & Nutritional needs which is & would be helpful & beneficial to my family. Especially with the economy as it stands at this stage of our lives we need as much help as there is to offer. Things are getting pretty scary with Trump at the helm creating all the inhumane chaos he can.
This should have never been able to happen in our country

Guissou Dabiri, Wynnewood, Pennsylvania

Dear Members of the Special Committee on Aging,

Community living matters to me because as a sibling of an individual with intellectual disability, I feel that this is the best situation for my brother and the entire family. The impact of programs like Medicaid HCBS have had a tremendous impact in our lives, as my brother would not thrive in other situations. His life would be miserable. He enjoys interacting with family and friends and other situations would increase his anger and depression.

I feel that the benefits of the HCBS is not unique to our family and that most other people with disabilities would prefer these programs. Continuations of these programs also have impact on the society as a whole.

Neva Capezza, Cobbs Lake Preserve, Pennsylvania

Dear Members of the Special Committee on Aging,

Community living matters to me because it provides a home environment and a family for people like my brother Dennis. The handicap are entitled to a community which is like home. My brother Dennis is very happy in the group home. Facilities don't provide the one on one care and environment for good care and needs of the individual. Facilities lack the personalized care and are breeding places for germs and disease.

Lynann Eller, Hollsopple, Pennsylvania

Dear Members of the Special Committee on Aging,

Community living matters to HCBS is the difference between stability and crisis for my family. As a disabled parent with limited income, these services allow me and my child to live safely at home instead of being pushed into unsafe or institutional settings. HCBS fills in the gaps that my disability and financial situation create — things like in-home support, medical care access, and the resources that allow me to keep our household stable.

Without HCBS, everything would fall apart very quickly. I would not be able to afford the basic medical and support services I rely on. My child's quality of life would suffer, and we would be at risk of losing our home or ending up in situations that are dangerous, traumatic, or completely inappropriate. These programs keep families like mine intact. They keep us functioning, healthy, and safe when there is no other safety net.

HCBS isn't a luxury — it's the foundation that allows me to live with dignity, remain independent, and continue caring for my child. Without it, the outcome would be devastating.me

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Kris Rhood, Sharon Hill, Pennsylvania

Dear Members of the Special Committee on Aging,

Community living matters to me because I know that I'm a capable adult who can and should live on my own with the proper support

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Statement for the Congressional Record
Submitted to the U.S. Senate Special Committee on Aging
Re: The Importance of Community-Based Services for Older Adults and People with Disabilities

My name is Nancy Murray and my husband and I have three adult children with an intellectual disability, one of who is experiencing early dementia. I am sharing our family experience to highlight an urgent and invisible gap in Medicaid Home and Community-Based Services (HCBS). Throughout the United States, the majority of adults with intellectual disability live at home with thier families and are on waiting lists; while others who have Medicaid waivers receive services from community based provider organizations. However, both families and provider organizations are faced with a serious lack of accessible, community-based dementia diagnostic resources for adults with intellectual disability, along with the absence of post-diagnostic supports that families desperately need.

Like many families, we began noticing subtle changes in my son's behavior when he was in his mid-50s—more confusion, withdrawn behavior, trouble or refusal to complete familiar tasks. He lives in a community home with staff who have known him for many years. Because adults with intellectual disability often cannot describe their symptoms, caregivers are usually the first to notice when something is "not quite right."

His primary care physician, psychiatrist and neurologist are well meaning but unfamiliar with the different ways dementia presents or how to diagnosis dementia in adults with intellectual disability, especially those with Down syndrome who face an extremely high Alzheimer's risk. We are fortuate that our city has a Down Syndrome Center with a physician who is knowledgeable about how to assess dementia in a person with a lifelong cognitive disability but we faced a multiple month wait for an appointment.Acording to the National Down Syndrome Society, only 5% of individuals with Down syndrome have access to a Down Syndrome Center and many families still have to travel long distances for appointments. Hence, many families often go years without a clear diagnosis or without the information and resources they need to understand the changes their loved one is experiencing and the absolute need to plan for the future.

This is why community-based diagnostic resources—embedded in HCBS, local disability agencies, or specialty geriatric services—are essential. When these services exist, families can access an early evaluation, medical rule-outs, dementia-capable care planning, and coaching on how to support their loved one at home or their community residence. These programs help prevent crises, emergency visits, and caregiver burnout.

Families should not have to navigate a fragmented maze of appointments and/or travel a long distance to learn whether their adult with intellectual disability has dementia and what they need to do next. Community-based diagnostic hubs, paired with post-diagnostic supports, allow people with disabilities to remain included, supported, and safe in their own homes which is exactly what HCBS aims to achieve.

As dementia becomes more common among adults with intellectual disability, especially those with Down syndrome, the need for accessible diagnostic and support services will only grow. Investing in community-based dementia-capable resources is not only cost-effective; it is a matter of equity, dignity, and honoring the right of all individuals with disabilities to age in place.

Thank you for considering my family's story and the tens of thousands of other families across the United States who need HCBS systems that recognize and respond to dementia in adults with intellectual disability.

Nancy Murray M.S.
Advocacy Liaison, William Penn Human Services
Chair, The Provider Alliance Government Affairs Committee
Board Chair, PA Assistive Technology Foundation
Board Member, National Task Group on Intellectual Disabilities and Dementia Practices (NTG)
Bethel Park, PA
njmurrayadv@gmail.com
412.216.6919

U.S. SENATE SPECIAL COMMITTEE ON AGING

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DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Rhode Island

Deanna Coleman, Providence, Rhode Island

Dear Members of the Special Committee on Aging,

Community living matters to me because reasons.

John Lancellotta, West Warwick, Rhode Island

Dear Members of the Special Committee on Aging,

Community living matters to me because - they are truly a GOD-send for millions of elderly & disabled citizens that need the vital assistance of trained CNAs and advocates to maintain a dignified presence in our communities - also it helps to keep aging and disabled Americans out of EXPENSIVE Nursing Facilities - use resources effectively! - Thank You

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U.S. SENATE SPECIAL COMMITTEE ON AGING

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DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from South Carolina

David Cottington, Rock Hill, South Carolina

Dear Members of the Special Committee on Aging,

My daughter has received various in-home services since her diagnosis of an in-utero stroke resulting in hemiplegia and cerebral palsy. It is unfortunately often that the doctor at the time of diagnosis will tell parents that their child will not be able to talk, walk, work, live independently, etc. It is only though home-based services including respite for the parents that a family is able to cope with the challenges that come for the rest of the parents and childs life. It has been absolutely invaluable for us.

Kristina Duff, Greer, South Carolina

Dear Members of the Special Committee on Aging,

Community living matters to me because my brothers are 55 yr old twins, and both cognitively disabled. They absolutely need support. They lived in a community in central FL and were so happy and proud. Their social needs were met, they had clean acceptable living standards. My aging mother can't do this at 81. I moved them to live with us in SC, they miss their independence, they feel depressed and just want to live in a community again. They need to be safe, gated community where they can't be taken advantage of. We need this in Upstate SC. They need ride support, they need respite care. They are awesome but unable to do this for themselves. Supported, Independent living in apartment communities especially created for this population.

Barbara Darnell, Sumter, South Carolina

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a son who is disabled who is on Medicaid and needs these organizations and services in order to survive, as well as manage his day to day living. Honestly without Medicaid and these community services is would just be devastating to us as a family.

Nicholas Gillard, Conway, South Carolina

Dear Members of the Special Committee on Aging,

Community living matters to me because I attend a program three days a week which is possible through HCBS . I have friends there and I have fun. The HCBS provides me with transportation

and I can do this without my parents which makes me feel more independent .My mother is helping me write this she worked for this program as a Medicaid service coordinator and helped a lot of people finds jobs and live a happy life

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Barbara Sloan, Conway, South Carolina

Dear Members of the Special Committee on Aging,

Community living matters to me because, as I grow older, I may very well need it. I have physical disabilities that sometimes affect my mobility and I suffer from long-term PTSD and major depression.

While I am able to maintain my own home now, I am close to 80 and realize that I may have to make other arrangements in the future.

Community living would give me more company and conversation, and possibly, more intellectual and activity outlets that may help me maintain my mental and physical wellbeing. I saw this with my father when he needed to live in a community setting. It was far better than his isolated existence at home alone.

I hope you will also consider the many, many people who cannot live on their own at any age, but who deserve the most supportive and least restrictive home setting possible to meet their needs. Everyone should be able to develop their interests and abilities to the greatest extent possible.

Victoria Jackson, Hardeeville, South Carolina

Dear Members of the Special Committee on Aging,

Community living matters to me because my son is 40 years old and unable to live on his own, and I am unable to live forever. Him being in a group home in the community has given him independence and security to me for his well-being for beyond when I am no longer here. As a parent this is a true gift from God to not have to worry about what will happen to him when I am no longer here. Thank you & God bless

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Submitted Written Testimony From
Disability Rights South Carolina For
The Senate Special Committee On Aging Hearing On
Aging in Place: The Impact of Community during the Holidays
December 3rd, 2025

Chairman Scott, Ranking Member Gillibrand, and other members of the committee, thank you for convening this hearing on an issue that is critical to South Carolinians with disabilities and older adults. Community is where South Carolinians live, access services, work, learn, and participate fully in all aspects of society.

Disability Rights South Carolina has been the mandated Protection and Advocacy (P&A) Organization since 1977. As the P&A for South Carolina, DRSC protects and advances the legal rights for individuals with disabilities. Our work includes monitoring and investigation of facilities and programs, offering information, training and resources, and legal representation on the legal rights for individuals with disabilities.

Community inclusion is essential for South Carolinians with disabilities and older adults because:

- It reduces isolation which lowers the risk of abuse, neglect, and financial exploitation.
- It ensures access to tailored resources and services while promoting awareness of rights, and
- It fosters shared experiences, peer support, and a sense of belonging through inclusive activities that encourage engagement and participation.

Disability Rights South Carolina advocates for all aspects of community living: education, accessible housing, employment, and transportation, and ensures services are delivered in the most appropriate integrated setting. Disability Rights South Carolina collaborates with organizations such as Independent Living Centers, Developmental Disabilities Councils, University Centers for Excellence in Developmental Disabilities, and others to achieve a society where South Carolinians with disabilities are fully included and recognized as integral members of their communities.

Each year, Disability Rights South Carolina submits Program Performance Reports (PPRs) that demonstrate the impact of our work. While these reports are not standardized, they consistently show how Disability Rights South Carolina advances community integration for South Carolinians with disabilities.

For example, in 2024:

- 2, 021, 158 South Carolinians received “appropriate community-based services or AT devices and services that promoted independence and integration” through programs such as the Protection and Advocacy for Individuals with Developmental Disabilities (PADD), the Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI), Protection and Advocacy for Assistive Technology (PAAT), and Protection and Advocacy for Voter Access (PAVA) programs. This number represents both individual and systemic advocacy effort.

- More than 90,510 South Carolinians with disabilities were also “able to remain in their own homes” through the work done in those programs.

  The Disability Rights South Carolina (DRSC) has been advocating for the development of a South Carolina Olmstead Plan to improve home and community-based services (HCBS) for individuals with disabilities. This initiative aims to hold the state accountable for addressing the gaps in HCBS that create barriers for individuals and their families.
  In February 2023, DRSC released a report titled ''Opportunities for South Carolina to Strengthen Home and Community-Based Services for People with Disabilities,'' which highlights the impact of the 1999 Olmstead v. L.C. decision and discusses the risks of institutionalization faced by many individuals in South Carolina.
  To raise awareness of these issues, DRSC launched a campaign highlighting the state's vulnerability to litigation stemming from the lack of a comprehensive Olmstead Plan. This campaign sparked conversations with legislators, and in January 2025, a Senate bill, S2, was introduced at the start of the legislative session. The bill proposed reorganizing three state agencies, the Departments of Mental Health, Disabilities and Special Needs, and Drug and Alcohol Services, into a single agency called the Department of Behavioral Health and Developmental Disabilities. This reorganization aims to address service gaps, particularly for individuals with dual diagnoses.
  Additionally, the bill called for the creation of a comprehensive South Carolina Olmstead Plan, involving the new Department of Health and Human Services and the Department of Public Health. It also included provisions for hiring a Community Integration Specialist and a State ADA Coordinator to oversee the development and implementation of the Olmstead Plan. Furthermore, an Olmstead Advisory Committee, consisting of individuals receiving home and community-based services, family members, and disability advocacy organizations, would be established to review and provide guidance to state agencies in creating the plan.
  Bill S2 was reviewed and passed by both the Senate and the House, and it was signed into law by Governor McMaster in May 2025.

In August 2025, DRSC met with the Governor's office to share insights from other states that have successfully implemented Olmstead Plans. DRSC will continue to monitor the implementation of this law to ensure that all recommendations outlined in the bill are executed effectively.
The impact of this bill is 80,871, the total SC census multiplied by the PAIDD factor of 0.0158.

- Under the Protection and Advocacy for Individual Rights (PAIR) program, 29% of clients served were aged 60 or older, and 79% of all PAIR clients lived in the community (independently, in a parent or family home, or in a community residential home living arrangement) rather than institutions.

Disability Rights South Carolina is at the forefront of ensuring these rights are realized across all areas of life: education, employment, housing, transportation, healthcare, etc. We work every day to make sure that South Carolinians with disabilities and older adults can live with dignity, independence, and fully participate in society.

We appreciate the committee's attention to this issue and look forward to continuing our work together to build a society where inclusion is not just an aspiration, but a reality for all. Should you have any questions, please feel free to reach out to Beth Franco, Executive Director at franco@disabilityrightssc.org or 803-782-0639.

Joy McGeorge, Huron, South Dakota

Dear Members of the Special Committee on Aging,

Medicaid and community-based services matters to my son and me because we both receive Medicaid. Also I have United Healthcare and Medicare. My son has ADHD, autism, depression, and anxiety. I've been struggling with my mental health since I was a teen. We have case managers, home health that does home visits. Last May, my son was at behavioral health urgent care for a week because he wanted to end his life. There are not a lot of programs like bigger cities have. There has been two shootings in our town. The last one happened on Halloween and another last year. Both victims didn't survive.

U.S. Senate Special Committee on Aging

"Aging in Place: The Impact of Community During the Holidays"

December 3, 2025

Statements for the Record

Statements from South Dakota

Joy McGeorge, Huron, South Dakota

Dear Members of the Special Committee on Aging,

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U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Tennessee

Jennifer Kirila, Murfreesboro, Tennessee

Dear Members of the Special Committee on Aging,

Community living matters to me because without Medicaid HCBS I wouldn't be able to stay in my home. I would end up more isolated than I already am. I would have to give up the few things and small pleasures in the world that really mean a lot to me, like my dogs and my many plants. These sound like small things that shouldn't mean so much, but when multiple chronic medical conditions have rapidly advanced and taken away everything that matters to you in life, the way you value and become grateful for the things that are left changes. I'm only 50. There is still a ton I don't have: I'm still mostly completely homebound since I don't have accessible transportation of my own, and some of my conditions aren't well controlled, so I still can't work at all because I'm unable to keep any sort of schedule. But I continue to work on bettering my health and try to find ideas for ways I might work again someday. I still have so many dreams and I want to make the biggest difference in my community and in the lives of others. People with disabilities - even multiple and severe ones like me - aren't worthless and we shouldn't be treated like we're invisible or our needs don't fully matter. Defunding these programs hurts society as a whole: Please, SEE ME! HEAR ME! I used to start nonprofits. I used to write things that educated people. I used to change the community I lived in in big ways. I could be that again. So many disabled people want this for themselves. I really feel like there should be broader funding for these programs for ALL disabled people, and it saddens me that there isn't. I fought with my state for over two years to be able to get the help I do get, and I'm grateful, and I think it needs to continue. I still implore you to consider this and more. It's easy to view people who aren't the same with conditions you don't understand firsthand as throw away, but so many of us have things to offer society that is going entirely untapped because the government views disability the same as less than. We may be a protected class, but believe me, we know what others think of us. The reality is just that disability means different. Every single person gets help from somewhere. Disabled people should be allowed to continue that as well, even those who need the help provided through Medicaid HCBS. Thank you for reading my letter.

Susan Gilliam, Lawrenceburg, Tennessee

Dear Members of the Special Committee on Aging,

Community living matters to me because we need people.

Janet Shouse, Franklin, Tennessee

Dear Members of the Special Committee on Aging,

I am the parent of a young man, 30, who has autism, an intellectual disability, ADHD and anxiety. He has extremely limited communication skills and intermittent but significant behavior issues. Community living matters to me because my son made it clear through his behavior when he was in his late teens that he no longer wanted to live with me and his father. He became a danger to himself, to us as his parents, to his twin brother, and others around him.

My son had been on our state's waiting list for Medicaid Waiver home- and community-based services for 11 years at that point, and he was fortunate at that crisis point to be enrolled in our 1915c waiver. But it took us two years to find a provider willing to provide supports to someone with his behavioral needs and close enough to our home that we could continue to be closely involved in his life and to remain in the town that he's lived in for 27 of his 30 years.

He has been in supported living for eight years now, and he's much happier. He still has meltdowns, but they are briefer and more intermittent. His staffers support him to do the things he likes to do, such as walk on our community's greenways and parks, swim at the local rec center, and visit the zoo and local museums.

My son requires 24/7 support, and he lives alone because of his behavior issues, so his supports and services are costly. I understand that, and I appreciate the fact that our state is providing these supports and service. But maintaining these supports requires a great deal of advocacy on the part of us as his family.

If drastic cuts were made to his waiver funding or supports, our family would face extreme difficulties. First of all, his father and I are in our late 60s, and physically unable to keep him safe or ourselves safe when he experiences a significant behavior incident. Second, his twin brother is now living in our home and has a 2-year-old daughter who is with us each weekend, and one of our autistic son's triggers is young children's voices and their crying. So it would be dangerous for his twin and our granddaughter if he were to lose his supports and have to move back home with us. We are not able to afford to pay for him a place to live with 24/7 staff. The Medicaid Waiver that he currently has allows him to live the life he wants in his own apartment, allows my husband and me to continue to work at our full-time jobs, and allows us, his twin brother and our granddaughter to live safely in our home.

Medicaid HCBS waivers are truly a lifeline for many of us. Please make sure funding is appropriate to serve the needs of people with disabilities.

Thank you.

Loren Storch, Clifton, Tennessee

Dear Members of the Special Committee on Aging,

Loren likes living in an apartment with a roommate. He is learning to be independent with day staff and night staff helping him with minimal instructions. Loren works 3 2 hours shifts 3 days a week putting pizza boxes together at Papa John's Pizza. Loren likes staff taking him out in the

community to go to places he likes to go to. Staff is helping Loren stick to a gluten free sugar free diet. Without Medicaid Loren would not have staff at Emory Valley Center to help him.

Kim Whitaker, Rocky Top, Tennessee

Dear Members of the Special Committee on Aging,

Community living matters to me because that is where all people live their best life!

Amanda Tackett, Clinton, Tennessee

Dear Members of the Special Committee on Aging,

Community living matters to me because so many of our individuals with disabilities are getting older. Their parents and families are getting older. If the individual still lives at home with their parents the parents will need to find arrangements for the future when they will no longer be able to support their child. Having community living supports allows families to have the comfort of knowing their family member is being well taken care of.

Amy M., Rogersville, Tennessee

Dear Members of the Special Committee on Aging,

Community living matters to me because we all need care and support from one another.

Frances M., Rogersville, Tennessee

Dear Members of the Special Committee on Aging,

Community living matters to me because we need to be there for each other.

Jerome Moses, Madisonville, Tennessee

Dear Members of the Special Committee on Aging,

Community living matters to me because IM DISABLED NEED HEALTH GYM EXERCISE , HEALTHY FOODS HEALTHY OVER ALL DIET AND TAKE CARE OF MYSELF

Gavin Anteau, Smyrna, Tennessee

Dear Members of the Special Committee on Aging,

Community living matters to me because if you don't have a community, what is there? People are nothing without community. Medicaid is detrimental to millions of Americans within our communities. I care about my community, do you care about yours?

Paula Dickerson, Harriman, Tennessee

Dear Members of the Special Committee on Aging,

Community living matters to me because I work with families that need support in their community to help their child reach their developmental milestones. Community programs and assistance help the families I serve gain more support and feel like they have a connection within their community.

Marilyn Bryan, Knoxville, Tennessee

Dear Members of the Special Committee on Aging,

Community living matters to me because my sister is special needs due to anoxia at birth. For many years she lived at home with our family. At around age 20 she had days when she wouldn't go to her day program. At this point the rest of the family all had needed jobs and college that couldn't be missed every day. We found a live-in program for her and reluctantly moved her into it. While this was very hard to have to do this their was really no other option. This program changed her life-gave her purpose and essentially another family to care about her. We visit frequently and while she loves our visits this has become her home and safe haven. She is now 72 years of age and would be very upset if this group home situation changed. I believe this program has been a godsend for her and our family as well as the others in this program and their families.

Amy Wood, Crossville, Tennessee

Dear Members of the Special Committee on Aging,

Community living matters to me because this affects my brother. He is disabled, and needs to have these agencies to help him live his best life. Thank you!

Shaun Fritts, Cleveland, Tennessee

Dear Members of the Special Committee on Aging,

Community living matters to me because I can continue to live independently and interact with the community and continue to continue my advocacy with family members and the person's served in the agency in the state of Tennessee

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U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Texas

Rene Aguilar, Fort Worth Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because IT ALLOWS ME TO STAY HOME WITH MY LOVING FAMILY AND BUILD REAL RELATIONSHIPS WITH FAMILY AND FRIENDS AND COMMUNITY GROUPS. LIVING AT HOME WITH MY FAMILY PROVIDES ME WITH SAFETY AND LOVE. I AM THEN OF CAPACITY TO BE PART OF SOCIETY.

Lois Chisholm, Fort Worth, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because we are 86 & 81. We need to be able to be near friends and family for support. We cannot get Medicaid even though our income seems to qualify. He has dementia and is totally incapable of caring for himself. Also, he has COPD, heart problems and is incontinent. I'm also a heart patient with diabetes, Dystonic tremor and 40+ allergies including gluten and nitrate. He was a minister 67 years and I was a chef. Normal and responsible lives but now we have to decide do we eat healthy food or put gas in the car so someone can drive us to the doctors appointments or, God forbid, do we need a heart medication we can't afford. If so, we beg drs for samples.
If not for family and friends, he would not have diapers to keep him comfortable between up to 6 baths a day.
Not because we are better than anyone, but many elderly are suffering in latter days because of greed and mishandling of Social Security and other programs. It's time to remove those able who will not work from assistance programs. Bring industry back to our country. Reclaim resources, repurpose and recycle everything possible. Put prisoners to work recycling instead of sitting watching tv. That could pay fines and restitution to victims. It can be done. Our forefathers worked very hard to build this great country. Time we restored it.

Donna Buckman, El Paso, Texas

Dear Members of the Special Committee on Aging,

CoI was a stressed out single mom trying to work a full time job and a second job I could do from home. I had a stroke at the age of 46 which left me paralyzed. I didn't have insurance at that time, but there was a program called CBA program, Community based assistance. Without that help I don't know what I would have done. It provided the means for me to live in a nursing home over the years. Community living matters to me because I still need assistance. I received therapy in the nursing homes and I made some progress, but need more help. because I'm still

paralyzed and with age comes new problems. Please don't remove help to those like myself otherwise we might all be paralyzed sleeping on the ground which I can't get down to the ground or get up from it.

Shari Joel, Arlington, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps me be independent. My granddaughter is high functioning autistic with anxiety disorders and has asthma. She has had 2 jobs. One through DARS, Workforce Solutions with Chuck E Cheese.
The job coach did not stay on site with her. The place made her work 8 hours without a lunch or breaks during her shift. Second job with Party City made her wear a mask during Covid. She almost passed out due to having Asthma and couldn't breathe. So she is unable to work. She was on SSI when she was 8 or 9 yrs old . She was kicked off . We have tried getting her back on SSI due to her being unable to work. She is turned down each time. SS says she doesn't qualify. When we go to the SS office we have been told she can't get SSI because she is white by 2 different people. My granddaughter is half white and half Mexican.

Mireya Dominguez, Austin, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because every older relative I have deserves a safe and respectful place to live and the means to do so

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Darlene Day, Forth Worth, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a 24/7 caregiver to my dementia mom since 2014. I had to quit my job 3 years ago due to BOTH my parents getting sick. Three months after my job loss, I lost my dad, non dementia.
I have no idea at my age 60 how I'm going to manage my life after being a non paid caregiver.

Steven Rosenberg, San Angelo, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because it's a choice

Tammy Weaver, Denison, Texas

Dear Members of the Special Committee on Aging,
How do programs like Medicaid home and community-based services (HCBS) impact your life?

What would happen if you didn't have them?

MY NAME IS TAMMY LOUISE ATKINS RECORD WEAVER, AND I AM A 65 YEAR OLD DISABILED WOMAN, PHYSICAL AND MENTAL DISABILITIES.. I WAS PUT TO WORK AT THE AGE OF 5 YRS OLD, I WORKED HARD, HONEST, BLESSED, AND THANKFUL. I WORKED MANY, MANY DIFFERENT JOBS, OWNED A COUPLE OF MY OWN BUSINESSES, ALWAYS WORKED HARD AND DID EVEN MORE THAN JOB DISCRIPTION, MADE SURE I DID EACH AND EVERY POSITION TO PERFECTION, EVEN IF I HAD TO EDUCATE MYSELF ON EVERYTHING IT CONSISTED OF AND BEYOND. I HAD 1 BIOLOGICAL SON, ADOPTED 2 DAUGHTERS, AND 1 SON, ALONG WITH COUNTLESS NIECES, NEPHEWS, AND MANY OTHER FOLKS KIDS, RAISED THEM TO DO THE SAME. THEN SUDDENLY I LOST MY BEST FRIEND, AND MOM, THATS WHEN I LOST ME, IN A SWIRL OF OLD ISSUES OF RAPE, JOB SEXUAL HARRASSMENT, GANG BANGS, BEATINGS, MUCH, MUCH MORE WHICH I HAD BLOCKED AS IF NONE EVER HAPPENED, UNTIL I LOST MY MAMA. THATS WHEN MY MENTALL DISABILITIES HIT ALONG WITH ALL THAT I HAD BLOCKED AND PULLED ME DONE INTO THE DARKEST OF DARK I NEVER IMAGINED. MHMR WAS THERE TO HELP ME GET STARTED BUT JUST NEVER BEEN ABLE TO GET ME BACK AGAIN, STILL. DURING THAT TIME I HAD BEEN SENT TO A PAIN MANAGEMENT DOCTOR WHICH SEEMS HE WAS ONLY CONCERNED WITH PRESCRIBING DRUGS, AND MORE DRUGS. HE ALSO PERFORMED INJECTIONS WHICH WERE OFTEN UNTIL THE LAST ONE WHICH CRIPPLED ME WORSE THAN I HAD EVER BEEN. I WAS INFORMED BY THE YOUNG MAN THAT INJECTED DRUG TO PUT YA ASLEEP FOR HE / DR. DIAMOND DID HIS INJECTIONS, BEFORE HE PUT ME TO SLEEP DR. DIAMOND MADE SEVERAL SEXUAL, RUDE, VULGER COMMENTS TO ME, THATS WHEN I FLEW OFF AT HIM W/O THINKING AND LET HIM KNOW HOW DISGUISED I WAS, AND PISSED, THATS WHEN HE KNOTED TO THE BOY AND ONCE I WAS OUT DR. DIAMOND SAID THAT HE WOULD FIX ME REAL GOOD, THATS WHEN HE INJECTED ME IN WRONG PLACE, INORDER TO CRIPPLE ME. THIS WAS TOLD TO ME A FEW DAYS AFTER, WHEN HE CALLED AND INFORMED ME. I COULDN'T STAND, WALK, OR ANYTHING AT ALL. I FINALLY WAS ABLE TO CRAWL AROUND ON MY HANDS AND KNEES, AND MUCH LATER I FINALLY GOT TO BE ABLE TO USE A CAIN, AND STILL TO TODAY. HAD I NOT HAD COMMUNITY SERVICES, MEDICAID, MEDICARE, ETC I WOULD HAVE COMMITTED SUICIDE, BUT WITH THE

VARIOUS SERVICES THSNK GOD I HAVE BEEN ABLE TO GET AND CONTINUE TO HAVE HELP, GET TO SEE DOCTORS, MY MEDICATION, FOOD, MUCH MORE THAT W/O I WOULD NOT HAVE KNOW ABOUT OR BEEN ABLE TO HELP ME NOT HURT SO BADLY, EAT, BATH, HAVE A ROOF OVER MY HEAD, COUNSELOR TO WORK WITH AND ALL THE SERVICES I HAVE HAD TO RELY ON EVERY DAY. IT HAS BEEN HARD TO BE A WORKAHOLIC, 6-7DAYS A WEEK, 12-18 HOURS A DAY, DOWN TO NOTHING. THE MANY KIDS I RAISED DON'T HAVE, WANT, OR CARE IF I AM ALIVE OR DEAD, IF I HAVE FOOD, PLACE TO LIVE, BILLS PAID, OR HAVE ANY KIND OF HELP. THEY DON'T CALL, TEXT, VISIT, BRING MY GRAND KIDS TO VISIT, IT IS LONELY, DARK, SCAREY, AND FEEL ABANDONED. WITH COMMUNITY SERVICES I HAVE MEALS ON WHEELS THAT BRINGS A MEAL DAILY, CHECK THAT I AM OKAY, EVEN HAVE A SHORT VISIT & CONVERSATION.. I AM BLESSED, GRATEFUL, THANKFUL FOR WHAT ALL I DO HAVE BUT LATELY THINGS ARE GETTING EVEN MORE SCAREY , WITH THE TALKS OF CUTS TO THIS, THAT, AND ALL. I JUST GOT OVER HALF OF MY SNAP BENEFITS WHICH IS CAUSING MORE STRESS ON HOW I WILL BE ABLE TO CONTINUE TO LIVE AT ALL, I HAVE AN EMOTIONAL PET, BEST FRIEND, 24/7/365 TO KEEP ME COMPANY, MAKE ME SMILE, &WORKS SO HARD TO KEEP ME FROM WORRYING, SCARED, CRYING. THAT CUT WENT TO THE BONE, AND IF YALL ALLOW ANY MORE CUTS, YOUR BASICALLY SAYING GO AHESD AND DYE BECAUSE EVEN THO YALL VOTED US IN TO PROTECT US, IT IS LOOKING LIKE WE DON'T MATTER AT ALL, INSTEAD THE WELL TO DOS, THE HIGHER UPS, PRESIDENT AND HIS LITTLE BUTT KISSERS ARE THE ONES THAT ARE BENEFITTING WITH OUR LOSES, THAT IS NOT THE WAY OF USA, AMERICA. SOMEWHERE ALONG THE WAY YALL GOT LOST AND SELF CONSUMED TO GET ALL YALL CAN AND THE HELL WITH US.
SO PLEASE STOP, THINK, LOOK AROUND, LOOK AT WHAT IS HAPPENING, TAKEN AWAY FROM THE VERY FOLKS YALL STATED YOU WOULD HELP AND PROTECT BUT INSTEAD WANT TO TAKE FROM US TO GIVE TO A DICTATOR WANNA BE. PLEASE I PRAY AND BEG OF YOU FOLKS TO DO THE RIGHT THING FOR US ALL, EVEN YOURSELVES CAN BE IN OUR SITUATION AT ANY POINT AND TIME.

PLEASE OPEN YOUR EYES, EARS, HEAD, & HEARTS AND DO AS YOU FOLKS ARE SUPPOSE TO AND HELP AND PROTECT US ALL NOW AND IN THE FUTURE. I PRAY THAT THE LORD TOUCHES EACH AND EVERY ONE OF YOU FOLKS AND CORRECT THESE ISSUES , STOP CUTTING US TO DEATH, AND PROTECT US ALL.

GOD BLESS YOU AND YOURS,

Tammy Doyle, Flower Mound, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because I am the caregiver of my 32-year-old profound autistic son who lives with us in our home. Currently there are no HCS group homes available for him to live in the staffing shortage in these group. Homes are very low the attendance only make in Texas $13 an hour so they're not very motivated to stay hired or have the training that's needed to be a Direct Care Workers. We are worried nonstop about what will happen to our son when we pass away. We are not wealthy and have no family to step in as we age. Currently there are no devices for the aging profound autistic s adults. Thank you for you help

---

Michael Grasselli, Carrollton, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because, my daughter has been suffering for too long. she was born breach 38 years ago. She had to wear a brace between her feet at age 6 months. She has been in a wheelchair since age twenty. She has been forced to be a human guinea pig most of her life. She is now having cardiovascular issues.

Kristy Pierce, Plainview, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because my 23 year old son is able to live with us and continue to be involved in community activities and be surrounded by family. If he were in a facility, he would be at least an hour away from those who know and support him best.

Pamela McKown, San Angelo, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter, Jennifer McKown, was one of the first persons to get into the Texas Medicaid Waiver Program known as HCS in 2000 at the age of 21! She has lived at home and learned to cook, wash clothes, clean house and become a valued member of our community. She is active at church and in Daughters of the American Revolution of which I am a member also. I have provided her transportation to doctors, dentists, dances, trips to see family and friends and all kinds of activities she would not have gotten had she not been supported by HCS. Through HCS she was able to get speech therapy and learn to read on a 5th grade level. I believe that without the support she has received from Lakes Regional MHMR

with Pace Opportunities being the provider and now Concho Valley MHMR with Daybreak being the provider, she would not be the happy, sweet, active and fun loving adult she is today.

Donna Reed, Spring, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter can live with me instead of an institution or Nursing home.

Evangelina Quintana, El Paso, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because it gives people with disabilities and older adults independence, dignity, and connection to their respective communities.

Tina Rodriguize, Fort Worth, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because
It allowed my mother to be at home. I am a nurse's daughter, and I had the privilege of taking care of her at home.. she didn't have to wait for somebody to help her because I was always available and she did not have to deal with the neglectful care of a nursing home. People deserve to be at home or one of our arrangement they have where they can thrive and be happy.. They are not animals. With the right support there is no reason for people not to be at home if that's what they choose.

Linda Trongone, San Antonio, Texas

Dear Members of the Special Committee on Aging,

Community living matters because means freedom to live in my community instead of in a nursing home or assisted living facility it's very important because I would like to have freedom in the community instead of a facility and it would be a lot cheaper than going to a nursing home or assisted-living facility please support this bill because it's important for all people with disabilities and older adults so they can have the right to live at home and then penally with supports and it would save more from people going ending up in the emergency room or hospitals and this is important I think someone should support this because disability rights is

human rights and aging people have the right to live in in place in their own homes instead of nursing homes or assisted living or any kind of institution hope you read my story thanks Linda Trongone from San Antonio Texas

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Sabrina Cantu, Richmond, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows my 21 yr old daughter to access therapies that help be able to be a part of community. She loves being social and going out to community events as well as going out to eat and shopping.

Marilynn Reeves, Iowa Park, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because after caring for family members placed in Nursing homes I have no desire to be there. I want to receive care in my own home and transferred to Hospice when the time comes.

Kristen Jones, Round Rock, Texas

Dear Members of the Special Committee on Aging,

My name is Kristen Jones, and I live in Round Rock, Texas. I am a person with quadriplegia resulting from a spinal cord injury, and I use a power wheelchair for mobility. I rely on Medicaid Home and Community-Based Services (HCBS) through Texas' STAR+PLUS program, including personal care attendant services that support my activities of daily living. These services allow me to live safely and independently in my community.

HCBS enables me to live a full, self-directed life. I work full-time for the State of Texas, teach as an adjunct professor at several Texas universities, hold a PhD, own my home, and serve on nonprofit boards and my homeowners association. I have had the same personal care attendant for 17 years—continuity of care that no institutional setting can replicate. This stability prevents health complications, emergency hospitalizations, and ensures my daily needs are met safely and consistently. I purchased my own home five years ago, and HCBS allows me to maintain housing stability and remain an active, contributing member of my community.

Even with a full-time salary and a second job, I could not afford the cost of care I require. My personal care attendant services alone cost nearly $50,000 per year, not including additional medical supplies that private insurance does not cover. HCBS is far less expensive than

institutional care, which nationally costs two to three times more per person annually. Without HCBS, I would likely be forced into a nursing facility—not because I need that level of care, but because the supports that allow me to live independently would no longer be available. Nursing facilities often provide poor quality care due to low reimbursement rates, chronic staffing shortages, and limited capacity to meet complex needs. These risks are not theoretical; they threaten the health and even the survival of people with significant disabilities. Moreover, ongoing Medicaid cuts have made it increasingly difficult for nursing facilities to accept Medicaid recipients, leaving people with nowhere safe to go.

HCBS allows me to work, pay taxes, teach, and contribute to my community, strengthening both families and the broader economy. It prevents unnecessary institutionalization, reduces long-term Medicaid expenditures, and allows people with disabilities and older adults to remain engaged and productive in society. These programs stabilize communities, enhance quality of life, and save taxpayer dollars.

I am fortunate to receive these supports, but thousands of Texans remain on multi-year waitlists for the same services. The need is urgent, and the return on investment is clear. I urge Congress to ensure sustainable HCBS funding, strengthen reimbursement rates, and expand access so that all Texans who need these services can live with dignity, independence, and safety.

Thank you for taking the time to hear my story and for recognizing the critical importance of Medicaid Home and Community-Based Services.

Carlos Alvarez, Austin, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because it’s what makes our society.

Michael Jones, Cypress, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because I have been working with children and adults with intellectual disabilities for many years. Most will not be able to integrate into our society. Having a place to live with people like themselves makes their lives much better. They can relate with their neighbors and function closely to them. Most places that provides those services have work opportunities for them. One place I work with has jobs that pay. This allows the individual to have a job, earn money, and be able to buy things on their own. They are not subject to the kind

of behavior that degrades and minimizes them as human beings. It's not something for children who need to be with their parents or other caregivers until they are more mature and have a desire to have their own life. The government, at every level, needs to be supportive of those programs. Having a life in which you feel accepted and supported is essential to have a life than one feels good about.

Susan Ponce, San Antonio, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because, No one knows Our daughter better than her Family and friends. Felicia has been able The program (CLASS) has been able to provide such care to partake in community activities and go out with the help of Family and friends and Attendants. Please take note that by taking away such programs, you are refusing to help Felicia from having individual care. Think about your own family, would you allow anyone else in nursing homes to act accordingly. People in nursing homes are abused and neglected. The help We receive is the best possible solution. Please DO NOT TAKE THESE PROGRAMS AWAY. They are very beneficial to the Care and Love received by family and friends and attendants. This is the ONLY WAY THAT FELICIA CAN COMMUNICATE WITH THE OUTSIDE WORLD. Felicia is not just some number on a page. She is living breathing Soul who deserves to be heard.

Joelene Moore, North Richland Hills, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because it’s important for all human beings to be together to learn, share, care, compassion, and a basic need.

Jessica Rothe, Liberty Hill, Texas

Dear Members of the Special Committee on Aging,

Community living and home health matters greatly to my family because it has allowed my son to go to college, get a degree, be with his peers, work, and be an active member in his community.

The personal care wages in my state are currently too low ($13 an hour), so it prevents me from hiring enough help to be able to work too. The cost of living is sky high where I live. The costs of being in the community living a full happy life vs an institution is 5 times more, so it is a win win for all. Money follows the person is smart, and actually it started in Texas to save a lot of

money which it does. If we prioritize care attendant wages, parents can work, and many with disabilities (but not all) can work as well. This brings in more taxes and happier and healthier people. There should be no asset limit (currently 2k total asset allowed), and they should be able to keep their Medicaid waiver services. Current federal law forces poverty on people with disabilities. We can fix this!

Linda Cox, Amarillo, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because our special-needs daughter with profound IDD, who lives in a group home, life depends on it! She is 24/7 total care. There's NO way one person could take care of her. It takes a team. Plus we as her parents are getting older and worry about her future. She has lived in a group home for 24 yrs now. It has been a GOD send for her and us as her parents
Lately, I've been extremely concerned with all the shutting down of HCS group homes due to budget cuts and rising costs of living. I have tried contacting all I know to make sure her rights are not violated and to be an advocate for her and all the others who depend on these services. We HAVE to be their voice!!
This DEEPLY CONCERNS me. I have physically seen the care of these people decline due to limited resources and staffing. It scares me actually for their future! They are the ones who suffer and they don't deserve to.
Please Please....
We DESPERATELY NEED you to come along side us and advocate to keep these HCS group homes and services opened and going strong to give these people proper care and housing. To keep them connected with their community and family and drs.
These are legal US citizens who depend on you! This IMPACTS their lives tremendously!
They need and rely on Medicaid and HCS as a means to survive and get the help they need.
They didn't ask to be born like this and they deserve to be taken care of in the best way possible!

Thank you for your ear and time!
I pray you find it in your heart to be the Biggest Advocate and Voice for these precious people and keep these services going strong!

Jack Jacobson, San Antonio, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because
I have multiple issues & it requires a community to deal with them!

Chuck Fattore, Richmond, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because i'm a quadriplegic person who cannot do anything for myself other than brush my teeth and feed myself. Medicaid's financial support allows me to have a 24/7 caregiver. Without her I would die.

Please note I live a very full life participating in numerous civic and religious communities. Let me encourage you to view this following video on how 14 people with Spinal Cord injuries live a fulfilling life.

YouTube
Type in: From Where I Sit UAB

Thank you for your support!
Chuck Fattore

Elizabeth Chamberlain, Arlington, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because I have an older brother who is living with I/DD and AU.
He was raised in a middle class family of 7 to be as included and involved with society as possible. He struggled with learning and managing his financial affairs. He was able to obtain employment but lost it due to inability. Later, he was placed in employment, which was successful for 37 years. He like all adults need autonomy and independence. At first he lived at the YMCA, where he became a victim. Later, he lived in supportive housing which is where he met his first ever friend. When that fell through, he and this friend lived in a condo that the parents provided. This was great for the guys but hard on the parents, especially because by now, our mother was a single parent. Family lived close and could do check ins. He took public transit to work each day.
If he had qualified for HCBS that would have made my parents financial future so much more secure and it would have offered him the community he had never had.
Blessedly, now he is in a supportive, rural community with others just like him. He is accepted and somewhat of a leader. Best of all , he is cared for physically, spiritually and socially.
Sadly, our state has long waiting lists for any HCBS services. While he qualifies, he is about 15000 on the lists.

This impacts my sole living parent tremendously and our family juggles a great deal to keep him in his dream environment where he is so happy. We hope to continue supporting him until his number comes up, but we all have limits ourselves. My mother frankly, just does without. Please think of these individuals and their families. They need dignity, respect and safety. Most of this population is subject to manipulation and predation. Help us keep them happy, healthy and safe.

Roy Moran, Georgetown, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because IT IS ONLY PLACE SENIOR CITIZEN CAN LIVE ECONOMICALLY SAFE

Judith Zwarun, Austin, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because I feel very isolated.

Lori Dugger, Sherman, Texas

Dear Members of the Special Committee on Aging,

How do programs like Medicaid home and community-based services (HCBS) impact your life? What would happen if you didn't have them? You act as if this is going to happen; it HAS happened. I am on SSDI I HAD Medicaid. My husband now qualifies for disability as well. Our actions caused neither, and we were forced to use these services, which you act as if no one had paid for in advance. Losing Medicaid has stopped all medication I was on, medications I needed to have a semi-everyday life. I have had to re-enroll in school to finish a degree I was unable to finish on medications, now, trying without and without funds. We are concerned about people who are worse off than we are, people older and in worse health, not only locked up, but in hiding and unable to get their medical concerns addressed. I am disgusted by what America has become. We all have failed her.

Shelby Scarbrough, Galveston, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because we all might need it one day - you never know.

Gina Velazquez, Garland, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter with Angelman syndrome non-verbal 23 mind of a 2 year old has needed her speech, occupational and physical therapy all her life. Specialists have done wonders from legs, scoliosis and disability dental. Needed anesthesia for all cleanings when approved. Recreational and music is also a big part of her life. When she visits movies, gyms, pools makes her and others smile too.

Michael Lassiter, Weatherford, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because without it I would surely be dead to be quite frank.

Luke Fain, Austin, Texas

Dear Members of the Special Committee on Aging,

Community living matters

Lyndal Waddy, Mineral Wells, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because it has been a total failure for this family. My son was born in 1964 with IDD and hyperactivity issues. At this time, help was inly available through State Supported Living Centers. James resided at Lufkin SSLC until age 54 when he passed from liver came. My nephew was born in 1974 with the same issues. Aaron died in 2007 as a result if mistreatment in a group home. My grandson was born in 1988 with the same issues. All three boys were non-verbal. In 1990 we learned of the genetic cause through intensive testing by a geneticist. The grandson lived in 3 group homes by 2 different providers ... disaster all the way around. He indicated 3 times he was sick and wanted help. The provider refused. His mother - a nurse - picked him up and realized he had a fever. He was taken to the ER where he was diagnosed with pneumonia and was placed in ICU fir a week. There were many other negative happenings. With the next provider, grandson acted out so the staff called the police and grandson was taken to the county hospital's psychiatric ward. Grandson was placed in a home with the county’s MHMR local authority … he hit staff and the police were called … he was

taken to the city jail and then to the county jail. This family is expert in care for IDD persons. The Arc IS NOT. Staff at group homes or community homes are nothing more than glorified baby sitters. They have no specialized training. The turnover horrendous. There are no meaningful oversight nor inspections if "group homes". The staff at State Supported Living Centers have superior training. I can assure you that communities do not welcome group homes and their residents. The Arc is not a friend.

Wayne Stalsworth, Seguin, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because my sister has had 20 strokes a heart valve replacement three stents she has diabetes and liver and kidney problems. Without Medicaid she would be kicked out of her Care facility and die. She has been a great contributor to societies and EMT and a respiratory therapist she deserves to live out the rest of her life!

Yasmeen Almasri, Irving, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because I have relatives who just retired and don't know how to live their lives. Also, for folks who are old & disabled, it's not that easy to find work or even apply online. Folks get rejected all the time due to them either being really old &/or disabled & the economy sucks.

Garry Kramchak, Houston, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because I want crime free neighborhoods.

Stephanie Flores, San Antonio, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter has Cerebral Palsy and needs the assistance even for the smallest things in life!

David Gibbs, Lewisville, Texas

Dear Members of the Special Committee on Aging,

My daughter has Autism and Seizure Disorder. She is non verbal and lacks 6 out 6 basic living skills. She requires care 24X7, Care for her is not a choice, it is a necessity. At best, she should qualify for Maximum funding, at least is her current Medicaid benefits. She is 30 years old and has not able to even tell you when she is sick or if she is in pain. I am writing today for those individuals who cannot advocate for themselves. I have paid my fair share of taxes all of my life but Texas believes in Corporate Welfare and gives Millionaires massive tax breaks.

Beverly Smith, San Antonio, Texas

Dear Members of the Special Committee on Aging,

I am a behavior analyst that works with adults with special needs. I see first-hand how this population and their families/providers live. Because behavior support was not available to these individuals when they were younger, learning takes more time. Think about how long it takes you to learn something as an adult vs. when you were a child. We were sponges when we were little! The different programs that are offered by the state literally change these people's lives. They allow them to learn new skills and decrease different problem behaviors. It let's them become as independent as they can be and less likely to need more support when they are older. In many ways, this is a lost population and Medicaid allows them to learn and grow and live.

Brenda Herrera, El Paso, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a daughter with special needs

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Brandon Bunch, College Station, Texas

Dear Members of the Special Committee on Aging,

If we didn’t have community living, then we wouldn’t have anything to do for special-needs people like us, and we wouldn’t be anywhere today without it.

Monica Williams, San Antonio, Texas

Dear Members of the Special Committee on Aging,

Community living matters to me because

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Utah

Cynthia Bingham, Ogden, Utah

Dear Members of the Special Committee on Aging,

Im writing this because I have a friend who has a 80-90 % blockage in her heart and Medicaid shut her off. She has always worked and try's to find ways to help others . And she has to walk around with this blockage and can't afford to get the medical care she needs because her Insurance won't pay for it . It breaks my heart to witness people good people who work all their lives and Medicaid shuts them out . This is America . God's will be done . Not billionaires. It's becoming very dark when Money is all power . It's scary ,sad and incomprehensible what's taking place right in front of eyes. Please help the people not the dark billionaires who don't care about people at all !

Brittany Bringhurst, Kaysville, Utah

Dear Members of Congress,

My name is Brittany Bringhurst, and I am the parent of Isabella, a 13-year-old girl with Down Syndrome and hearing loss. Isabella is currently covered by Medicaid in Utah under a Limited Waiver from DSPD. I am writing to share why programs like Medicaid Home and Community-Based Services (HCBS) are essential for families like mine.

HCBS allows Isabella to live at home, attend school, and participate in her community with dignity and independence. These services provide critical supports such as therapies, assistive technology, and respite care that make it possible for her to thrive in a family setting rather than in an institution. Without HCBS, Isabella would lose access to the resources she needs to communicate, learn, and grow. Our family would face overwhelming financial and emotional strain, and Isabella's opportunities for inclusion would disappear.

If these programs were not available, the alternative would be heartbreaking: isolation, institutional care, and a loss of the progress she has worked so hard to achieve. HCBS is not just a service—it is the foundation that allows my daughter to be part of her school, her community, and our family life.

People with disabilities deserve to live with independence, dignity, and connection. HCBS makes that possible. Please protect and strengthen these programs so that children like Isabella can continue to live and thrive in their communities.

Thank you for listening to our story and for your commitment to ensuring that all Americans have the opportunity to live full and meaningful lives.

Tracy Oliver, Millcreek, Utah

Dear Members of the Special Committee on Aging,

This topic is one that really gets me kind of heated. It's tied to the economy and the fact that the cost of living is so damn high. But not just that. I suffer from mental illness. My body is starting to give out on me now also I but I have to work full time and still can't afford to support myself. The department of workforce services, however couldn't wait to take all of my benefits in fact they took them almost immediately. Yet I was told I couldn't refuse work. This is an insane way to do things in my opinion. I pay for insurance through my employer. However with the deductible as high as it is I can't afford to use it. My meditation for my mental illness alone is over 800 a month. I was denied social security back in 2015after breaking my back and a five year fight. Due to a prior drug addiction. Which blew my mind I know a lot I mean a lot of addicts who are on social security. In fact my ex husband who is an addict and has never held a job received social security because he is institutionalized and I can't get it because of a prior history. WTH. Then there is the millions of illegal immigrants who get new cars insurance monthly payments and down payment for a home. Why can't I get to the same hand up. I struggled my whole life and am now almost fifty and can't afford my rent in my tax accredited low rent apartment complex. Let alone food and everything else. I work my ass off for 15 dollars an hour. It's not right. So there you have it this is my experience with these programs. In my opinion there needs to be a complete reform in terms of all this that for once actually helps hard working people and not just the immigrants and dregs of society.

Jonah Nelson, Salt Lake City, Utah

Dear Members of the Special Committee on Aging,

Community living matters to me because I have basic level human empathy for my fellow man. I know those that grew up in privilege can't comprehend the meaning of struggling and feeling for other human beings but you should know most people do

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U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Vermont

Maura Lane, Waitsfield, Vermont

Dear Members of the Special Committee on Aging,

Community living matters to me because my son is 45 years old and still lives with me. My husband and I are both in our 70's. I would really like my son to find a service supported home before we are no longer around.

Anna Spahr, Rutland, Vermont

Dear Members of the Special Committee on Aging,

Community living matters to me because, like our lives depend on it at this point, after these republicans and there leader are trying to distroy what we stand for, WE THE PEOPLE DO NOT BOW DOWN TO KINGS!!!!!! for one, and we as a community must stick together!!!!!

Kenneth Carpentier, Starksboro, Vermont

Dear Members of the Special Committee on Aging,

so now at the age of 70 now . I seen all the years i help comfort and tried to get foods for my senior peers and Some of them suffering veterans . I can say with out the food shelf and my unpaid time to care for them. Leads me to believe if you cannot help your community and fellow man then we our lost. many of the people i cared for over the years were suffering in the communities. they wanted to stay independent but the support was very low from helps they needed live in there communities . The worsts suffer age being unable to afford medical care. So i am just going to say it is very import to try to maintain community help and support . Life matters in every community and those who had been removed to nursing homes give up and die . death rates in nursing homes and abusive action in those homes should be under investigation. At 70 yo age if i have to leave my home of 30 years then i will suffer lack of care and concern of my fellow citizen. So it matters to me and all those i get to . that are volunteer community support systems. if only the world could get that every community matters for it is the strength of our nation . it is dying. So i hope this message helps show that community matters and doing your best to help your fellow citizens is very important. Other wise we are going to see more murders and chaos. thank you. All lives matter. we need to get back on track. okay done.

U.S. Senate Special Committee on Aging

"Aging in Place: The Impact of Community During the Holidays"

December 3, 2025

Statements for the Record

Statements from Virginia

To Whom It May Concern:

My family's journey in the world of individuals with disabilities started 26 years ago. My daughter was born without the suck, swallow and breathe reflex. That is the function babies are worn with and is needed to suck a bottle. She was immediately diagnosed with failure to thrive. She ended up in the hospital an additional five days before she was allowed to go home. We had to continue to take her to the pediatrician every day for a weigh in to ensure her weight was increasing ounce by ounce by ounce. After an appointment with a speech therapist at the age of 30 days and still struggling to eat, that was her life-changing moment. The therapist basically had to teach her tongue and mouth muscles how to suck her bottle. This reflex is something most are born with. Some need a little extra help.
That was the beginning of the journey that we have been on for over 26 years now.

Nothing about this journey has been simple or easy. I had to quit my job when it became apparent my daughter needed me more than any job would ever tolerate my absences and the need to take care of my daughter vs working for a thankless company. I have used my skills to advocate, educate and help my community navigate the quagmire of all of it.

We fought many battles with the public school system, which most likely shortened my life by 10 years. Many individuals in higher positions of authority created hostile meetings. I will never understand their thought process when the answer was "no" to many simple requests. Even if they had said yes at times and put it in writing in the IEP, I would find out later it was a lie, and they never followed the IEP with the requested and agreed upon accommodation/s. Looking back, I would wish those stressful, anxiety filled days never existed. Why do we have to fight so hard for the nurse to change a pull-up? Aren't nurses in schools to help with incontinence? And do not get me started on individuals with disabilities being left out of field trips. The typical person does not have hours and hours and days and days to spend on researching the laws and what a public school is supposed to help with.

I always like to say the phrase "pay me now or pay me later." Which equates to invest in them now when they are younger, or you will be investing in them much more, later when they are older and have more needs because their parents or caregivers are no longer around. It is extremely important and vital to this success of any individual with disabilities to receive instruction in academics and a lot of activities of daily living. I see so many older adults who have no idea how to sort clothes or brush their teeth correctly or change their clothes to appropriate weather and put on in the correct orientation. So many things' adults need help with could be addressed at the public-school level. Their days should be geared towards the things an individual will need as an adult trying to live independently. I so wish I could have seen my daughter at 26 during many years of fighting for academics when it was clear she would never hold a job because of the severity of her disability. We need to invest in these individuals when they are younger and as they reach high school level emphasize and make sure the individual is getting some sort of benefit besides being free janitors in the public school and in local businesses. These businesses are happy to have the individuals with disabilities come in and clean their stores, restock for them, unpack orders and many other things they can

do. Once the individual graduates none or very few of these businesses hire that individual. Yet they happily take all of them for any free labor, disguised as volunteerism.

As I replay and relive the years and years of advocating for my daughter and ensuring she qualifies for benefits that she is entitled to, I am beyond exhausted trying to prove every year she is still eligible. She needs her waiver to continue living a somewhat meaningful quality of life.

Which leads me into the discussion of Medicaid waivers. The waivers were created for people with Intellectual Disabilities and/or Developmental Delays. My daughter could not even apply and get on the waiting list until she turned 6 years old. She then had to wait another 10 years to receive a waiver slot. This was when the waivers were operating on the waiting list method and the individual moved up the ladder as slots became available.

Now the waiver system is completely out of control. Ever since Governor Youngkin funded all Priority 1 individuals on a waiver waiting list, it is being grossly misused and abused. What used to be a very controlled publicly funded way for adult adults with disabilities to attend an adult day program, and/or live in a group home, this waiver has morphed into a way of life for parents/caregivers to make a living off of their individual with disabilities, and some do not even have a disability. Speculation and guessing is the norm now when a young child is moved to the front of the line. Some do not even have a diagnosis yet and a 4-year-old on the list. I do not know when the waiver criteria changed to include 2-10 year-oldsin the massive numbers they are now showing up on. They are now being added to the waiver list as Priority 1 because of behaviojrial issues that cannot be control. REALLY? A parent cannot control their 4 year old so they want more hours to get paid so they can not parent them even more – AND GET PAID FOR IT – with tax dollars needed for adults! These are children whose parents do not want to parent. Period. These are children being pushed through the waiver to priority one under the fake guise of having behavioral issues.

A three-year-old with a behavioral issue. Say that again out loud. A three-year-old with a behavioral issue. I've also seen the criteria say this individual requires a waiver because he destroys his sister 's toys. Not one of us would ever think a seven-year-old who gets angry at his sister and rips the Barbie doll head off would require the care to go into a nursing home because of his behavioral issues. It is a lack of parenting and a lack of parents providing consequences to children, who basically are just throwing the typical temper tantrum. How we have gone from allowing children to have a temper tantrum to saying they are a danger to themselves and others and require a waiver in order for the parent to get paid is absolutely ludacris and a waste of taxpayer dollars. None of these children below the age of six should even be considered for a waiver, unless they are seriously medically fragile. Which they are not based on the rest of the information provided.

I don't know who at DMAS changed the criteria to allow the younger children to take the slot of a 35-year-old whose mother is dying of cancer and their father has passed away. Their only sibling lives six states away and does not want to take responsibility for this individual. That is

where we are with this waiver system that is being abused by case managers and supervisors who allow 3, 4, 5-year-olds to be pushed through to this waiver waitlist—and they get that coveted waiver some other individual has been waiting 25 years to obtain. I'll say it again none of these children should be on this waiver unless they are critically medically fragile and need round the clock nursing care. The waiver is meant to provide for adults with disabilities. HOW DID IT GET SO DISTORTED? The only thing these parents want out of this waiver is to get more hours to be paid to do their job that is required of them by the Commonwealth of Virginia. Parents are responsible for their children until they reach the age of 18. Since when do we the taxpayer pay parents to parent? The entire system needs another look at.

The absolute most ridiculous thing that I have been told is if a person receives a diagnosis of autism, they automatically are approved to get on the waiver. Just because someone has autism does not mean they should be allowed to be pushed through to the top of the line and put on as a priority one. Autism is being severely over diagnosed because it is the flavor of the moment. Many autism diagnoses do not come with a diagnosis of an Intellectual Disability or a Developmental Disability. Please stop putting children on these waivers that were created and designed for adults with disabilities. Some of these adults have been on that waiting list for 25 years or more. We have got to stop giving them to children and make the parents do their jobs by parenting them and pushing these parents to get a job. Paying parents to take care of their minor children is not being fiscally responsible with the tax dollars of your constituents. Many of these families also get Medicaid, thousands in SNAP Benefits, and every other Title 1 out there. Leave these Waivers for the adults they are intended for!

When did a diagnosis of autism automatically qualify an individual for a waiver? Many are just socially awkward. The justification for needing a waiver is often invalid as well for minors. When caseworkers try to justify a four-year-old needs a waiver because of behavioral issues, they are flat out lying. When case managers write up a 4 year olds behavior cannot be managed or controlled with current therapies, medications, and methodologies, and they need this waiver to access such and such service, these children are ***already eligible*** for the service through Medicaid that they already have or through the public school system. There are many services they are already eligible for through their public schools. Which brings you back around to people just not knowing what is available and what they can already access. Many many, many of these parents say they can't handle the child's outburst, and the case manager approves them for a waiver. I do not understand if a parent says they cannot manage their child's behavior but that's why they need a waiver. Then you find out that they need/want the waiver because the child's hours were cut back from 40 hours a week to seven on the CCC+ and the Case manager is pushing them to a full-blown waiver. The parent is often very vocal saying "I can't live on this and I can't deal with my child." So how can you say your child is out of control and needs help but in the next sentence you say if I had more hours that paid me to watch my own child, then it would be better. Makes no sense!

The parents' responsibility does not end until the child is 18, no matter what. We should not be paying parents to care for their children who need discipline, structure, and engaged parents.

Parents/Caregivers need reminder their hours were not cut. The hours do not belong to them. The hours belong to their disabled child.

PLEASE revisit the waiver system, put some guard rails back in place so every child with even a whisper of the diagnosis of autism is not pushed through. Not everyone with autism has ID or DD. Many go on to live rewarding, fulfilling and successful lives. Can you imagine if Bill Gates parents just accepted his autism diagnosis and had a caregiver/paid caregiver brought in for him? Or Albert Einstein? There are many other famous well-known individuals who were absolutely on the spectrum who did not need taxpayer dollars paying their parents to stay on their phone a little bit longer and ignoring the needs of their child a little longer – which results in behavior issues!

I apologize for the length of this letter. I have been very angry for over a year as I watch such young children get a waiver that should have gone to the 45-year-old living in a hotel, no transportation, and isolated.

Thanks for your time and staying with me this long. I sincerely appreciate all you do.

Tammy Adgate
Marshall, VA

New River Valley Coalitions Support Healthy and Safe Aging

By Ray Parks, Pulaski, Virginia

As an older adult now living and working in the New River Valley region of southwest Virginia, I appreciate the tremendous effort and leadership put forward by a host of professionals, stakeholders, agencies, and volunteers to create vital, supportive communities for aging in place. This area is home to a diverse array of demographics and resources, from the thriving Virginia Tech University complex to the extremely rural countryside bordering the West Virginia state line.

My professional stake here is to oversee the New River Valley Agency on Aging (NRVAOA) as its Executive Director. NRVAOA just celebrated its 50th anniversary this year under the federal authorization of the Older Americans Act and the state regulation of the Virginia Department for Aging and Rehabilitative Services. Five local governments chip in to form a joint exercise of powers operation providing nutrition, transportation, information & referral, ombudsman, insurance counseling services, and much more for older adults and their caregivers.

The strain of finding, or providing, care in many circumstances can lead to crisis situations as demonstrated in increasing rates of suicide, poverty, and homelessness. No one entity alone can adequately meet the service needs.

The real power of these efforts lies in the willingness of the academic community, churches, human service agencies, civic groups, businesses, and volunteers to join forces and leverage each other's capacities to make a positive impact on the real issues that--to varying degrees--may surround all of us as we grow older; i.e., losses in human connection, mobility, food security, health, and financial resources.

I have witnessed examples of vital community-based organizations networking here to achieve important results. THRIVE addresses food insecurity, PATH impacts health outcomes, and Aging in Community provides tremendous guidance for planning and navigating life changes in multiple areas. Individuals with these kinds of supports maintain status much longer as residents who are active participants in the life of the region, rather than just patients to be cared for or institutionalized. I am convinced that the economic and social quality of life here can only benefit.

Pamela Treer, Ashburn, VA

Dear Members of the Special Committee on Aging,

Community living matters to me because due to a divorce my son no longer has financial support from his father. I work 2 jobs just to help him with groceries living paycheck to paycheck in Virginia. In 2025 , 5 years post divorce , due to his disability support with his Medicaid waiver, SSDI and SRAP in Loudoun County, was granted a housing voucher with in home support. The disability community has been severely impacted by COVID shutdown and now the most recent government shutdown. I urge our government to find funding to support the needs of the disabled community all across our communities.

Phyllis Hagmaier, Williamsburg, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because I can talk to my friend and learn of news this that are happening

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Adriana Sturdevant, Gainesville, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because I have an adult son who was born with a genetic anomaly. He will never been able to live independently. HCBS are so important for people like him in many ways. Once people with disabilities age out of the school system there are very few programs available, HCBS fills that gap. What it means for him is a community, friends, a sense of purpose, a place where he can continue to learn and grow with his peers. As his parent, I know I won't always be here to care for him or manage his care, HCBS is the safety net for him. If my son did not have his day program there would be nowhere for him to go, it just doesn't exist outside of the system. As he ages and I age these programs become even more critical not just for his quality of life but his LIFE. It cannot be overstated how important these programs are for my son and others who rely on them.

Laurie Carrero, Williamsburg, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because our daughter spends money in our community and

The people helping her with her transactions recognize and acknowledge her importance. She feels that she is included, and part of her community. She can also help the community. By donating items to the Salvation Army so others may benefit . We teach her, you may need help, but we can also help others in the Community. Anything is appreciated. Please hear her voice-she is non verbal. Thank you.

Heather Heflin, Burke, Virginia

Dear Members of the Special Committee on Aging,

HCBS Medicaid funding makes it possible for people with disabilities like me to not only live in communities but to thrive. Without it my future would be very uncertain. You have a great opportunity to make a very positive impact on the lives of millions of Americans with disabilities.

Sandra Cleva, Falls Church, Virginia

Dear Members of the Special Committee on Aging,

Programs like Medicaid HCBS allow adults with intellectual disabilities to truly be part of the community. I've seen how important this is as a volunteer at L'Arche GWDC's home for life on Highland Street in Arlington County.

Four "core members" enjoy life as family, building lifelong relationships within the home, in the neighborhood and across the community. Their interests range from softball, gym workouts, and swimming to community theatre, reading, gardening, and watching Star Trek reruns.

My husband, who has also been a L'Arche volunteer, had an uncle who had intellectual disabilities. The family had no option except to warehouse him in an institution since no one was available to help him navigate the community. Options like the L'Arche homes for life were not available then.

Please ensure that adults with intellectual disabilities continue to have access to a fulfilling and empowering living environment -- a setting made possible in part through the Medicaid program.

Cynthia Leonard, Richmond, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because it's very important for people with disabilities to remain independent.

Esther Baldivia, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because my intellectually disabled son is able to develop social skills outside of my home. Although he is able to work in a special needs workplace, he could never afford rent without rental assistance that he receives. I just wish the annual application process was not so overwhelmingly burdensome. One sole person in the county handles about 150 cases all within a few weeks of the application window. As I age, I worry about who will help him with this when I no longer can.

James Mather, Lorton, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because without community we have nothing.

Kathleen Walsh, Alexandria, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because I have two autistic, 17–year-olds, with relatively low support needs who will not be able to get jobs and live lives where they will be able to contribute to society without community living.

My biggest concern is where and how they will live after we pass away and before, when we become too old to care for them.

The supports they need are not available privately. No amount of private money can buy them.

Will my disabled adult children become homeless, all for the lack of a job coach, or someone check in on them or to remind them to do what they need to do to take care of themselves?

Is the only way to keep a roof over their head going to be institutionalizing them?

That's what we did to people 60 years ago.

The Supreme Court declared that they have a right to live in the community like everyone else.

Beyond the moral imperative, it is less expensive to house And support people in the community than it is to institutionalize them.

I can't sleep at night, worrying about what will happen To my disabled adult children after I am no longer able to care for them, if these supports do not exist.

Thank you.

Greta Selden, Mechanicsville, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because my husband and I are caregivers for our adult son with profound autism. He needs 24/7 care. There are many families like ours who rely on HCBS.

Gayle Dillon, Montpelier, Virginia

Dear Members of the Special Committee on Aging,

As an advocate and care provider, I see firsthand every single day how people thrive when given choices in their lives. Little is more impactful than a person knowing their desires, dreams and needs are respected. The value of HCBS in our community can't be underestimated and must be protected. I can not imagine the harm our most vulnerable and deserving citizens if the funding provided through Medicaid programs that support HCBS living is reduced.

Respectfully,
Gayle Dillon, M.Ed
Group Home Provider
Community Program Director
Former Publix School Educator
Lifelong Advocate

Teresa Bohan, Alexandria, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because it is the essence of humanity.

Steven Urquhart, Roanoke, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because the GOP is trying to make America into Nazi Germany!

Kiana Mitchell, Linton Hall, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because part of the beauty of life is meeting people from all walks of life. There is so much to learn from people who are fundamentally different from you, and I think it's amazing. The elderly and disabled people deserve to have safe housing that can support them and their needs. Knowing that those who are near and dear to us are being well taken care of can give us peace of mind, especially as our family members advance in age. Not everyone has the financial or mental capacity to provide for family members with increased medical needs, so programs like Medicaid HCBS are crucial. Please support programs like this.

Pam Schoppert, Leesburg, Virginia

Dear Members of the Special Committee on Aging,

Community living is essential for our 18-year-old daughter Eliza because it supports the independence and adult life she has worked so hard to achieve. Eliza has Down syndrome and worked hard to graduate with a standard diploma from the same public high school that her big sisters attended. Throughout her school years, she thrived in inclusive environments that valued her abilities and empowered her voice. Now, as a young adult, she deserves the same opportunity to continue that growth in real-world settings where she can build relationships, develop skills, and pursue her dreams.

Our daughter is already deeply engaged in her community. She performs with the Arts for All theatre program, where she has built confidence, friendships, and a true sense of belonging. She proudly participates in Special Olympics sports, where she enjoys being part of a competitive, supportive community. Every week, she volunteers at both the local hospital and the animal shelter, giving her time and energy to help others—work that brings her incredible pride and purpose. On top of all of this, she is taking college courses at our local community college, demonstrating her commitment to continued learning and her readiness for greater independence.

These experiences aren't just activities—they are evidence of the full, vibrant life she is already building. Community living would allow her to take the next steps in that journey. It gives her the chance to make age-appropriate choices, manage responsibilities, and deepen her independence with the right supports in place. It also enables her to grow socially while staying connected to the programs and people who enrich her life.

Most importantly, Eliza wants to be independent. She desires a life where she can contribute, connect, and flourish just like any other young adult. Community living honors that desire by providing both safety and freedom. It creates the bridge from high school to adulthood in a way that aligns with her goals, reflects her potential, and respects her right to a meaningful life.

For her—and for our family—community living is not only appropriate, but also necessary. It allows her to continue the purposeful, engaged, and independent life she is already working to build, and it gives her the inclusive future she deserves.

Please continue to support programs like Medicaid HCBS for Eliza, and other young adults like her.

Norman Faria, Roanoke, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because it's how many of us survive. Medicaid HCBS helps me get the assistance I need for mental health, skill building and primary care. If I didn't have them, I'm not sure what I would do because it would be difficult functioning without them. I've learned essential skills to help me be a better person, received medication management, counseling, medical and dietary advice. I am grateful. Happy holidays!

Elliot Johnna, Blacksburg, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because 2 of my students in special education lost their mom when they were teenagers back in 2000. They both have significant disabilities and they literally had no where to go and no family member willing to take them. As a transition coordinator, I was able to help both of them get the Medicaid waiver and move into sponsored residential homes in our area. Now, as their guardian, I can depend on the community service board and local agencies to manage and maintain their services. They both love living with their respective families. They both participate in a wide range of community activities. Without Medicaid

waiver and the excellent support systems developed in Virginia, they would be homeless or institutionalized. Community based services saved their lives!

Donna Payne, Virginia Beach, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a 44 year old son with intellectual disability from birth. He has always been with me but I'm 77 and dread leaving him. He has SSDI and works but to do that he has a job coach from the city and I drive him to work and back and if either of those things fell out it would be very bad for him.

Debra Chappell, Wytheville, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because, I want to stay in my home. My sister is my paid caregiver. Without the Medicaid program. I would not be able to stay with my sister in our home. Because she has to make a living also. And it keeps me out of a nursing home. Where I have to worry about my health and safety. Thank you!

Joseph Anthony, Buckingham, Virginia

Dear Members of the Special Committee on Aging,

My adult daughter has Down syndrome and autism, as well as an anxiety disorder with OCD, and leans heavily on the support provided by her Medicaid HCBS. Without it, her quality of life would evaporate, and her connection to her community would disappear. She is completely incapable of caring for herself. With the help currently in place, she is immensely happier and more functional. Thank you for your time.

Nick Zweerink, Richmond, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because as someone with mild IDD I can’t live without it like everyone with disability that’s living on their benefits

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Piotr Sliwka, Manassas Park, Virginia

Dear Members of the Special Committee on Aging,

Please, do reverse all deep cuts to Medicaid, including all work requirements before 12/31/26. Thank you.

Terry Scott, Culpeper, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because,
How do programs like Medicaid HCBS impact your life? The programs have helped me thru very difficult times dealing with the brain cancer I have. It has and continues to allow me to be able to reach out to others even though I may be isolated due to my illness and know that I have a safe place to talk about any issue I may have.
What would happen if you or someone you know didn't have them? I would feel more isolated and the chance to receive any help I need would be gone. When you have to face dying and death like I have had to so far any amount of encouragement is a blessing from Heaven for sure.

Susan Dixon, Norfolk, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because I am currently living with three disabilities, HS, Fibromyalgia and spinal stenosis. I have always worked in spite of my disabilities until last year when I was diagnosed with Stage IV Hodgkin's Lymphoma. I under went 6 months of chemo therapy which greatly impacted my strength and cognitive abilities. My job at the time was very physically and mentally demanding and they would not keep me on light duty for the 6 months I needed to recover. I lost my home, my job, my insurance all in one go. I had to move in with a family member, but due to the horrible private Healthcare system in America, I could not get medical coverage. To top it all off my other disabilities were aggravated by the chemo, so my recovery from cancer has been even slower. My blood must be monitored for 6 years because of my cancer and as soon as I lost my health insurance the cancer center where I was treated, who charged and was paid over 2 million dollars for my treatment, canceled all future appointments. I applied for financial aid through their in house program and was denied. I had no recourse left but to apply for Medicaid for the first time in my life. I have always prided myself for working and providing myself, my children and my spouse with medical health insurance, so it was a humbling experience to have to even ask for assistance in this way. However, having a chest port that needs to be flushed monthly so I do not develop blood clots, as well as continued monitoring of my blood for return of the cancer left me no choice. I have recently learned my cancer has returned after only 6 months of remission. I live in fear that Medicaid will be ripped away from

me before treatment can be completed and I will be forced to just accept my own death at just 56 years of age. The stress of that adds to the burden of my other disabilities as it causes flairs making me weaker and harder to move forward with my life. I live every day in fear that a system I have worked and paid into will be ripped away by people who have never had to struggle.

Claire Terracciano, Burkeville, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because I don't have to deal with neighbors

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Lisa Giamette, Culpeper, Virginia

Dear Members of the Special Committee on Aging,

Community living matters to our family because of my second child.

Josh has a rare genetic disorder called Phelan-McDermid Syndrome. Josh also has been diagnosed as autistic (level 3) and has focal epilepsy. Josh requires full 1:1 support with all of his daily activities. He also is nonspeaking and currently does not have a way to communicate his wants and needs efficiently.

The services Josh receives from his Community Living Waiver allow him to thrive in our home and his school. He is also able to get out into our local community to engage in activities. Josh thrives on routines and relies on his caregivers understanding his needs. This waiver allows us to hire the caregivers who best understand and support Josh.

Without these services, Josh would be at risk for being placed in an institution. I'm a single mom and could not meet all of his needs on my own while also providing for my other children. Josh's needs are such that I cannot simply leave him with an average babysitter and no after school program exists for his needs.

When fully supported in an environment where he is comfortable and understood, Josh is what my father used to call "unfiltered joy". Josh loves life and smiles, dances, and "sings" through his days.

If Josh were to be placed in an institution, I honestly believe that who he is would begin to fade. When Josh has been forced to be in unfamiliar surroundings, he quickly can get frustrated. He engages in self-injurious behavior (he harms himself) or he can lash out at others. He also tries to

escape unfamiliar places.

Please continue to support the Community Based Services. My son Josh, and others like him, deserve to live where they can be comfortable, cared for, and where they can thrive.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Washington

Teri McKeehan, Everett, Washington

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter's life is highly impacted by autism. She needs 24-hour care and supervision for her safety and to thrive.
She pays her own rent to share a home with 4 other clients, and is supported by loving and devoted care workers who are also paid by Medicaid.
Without Medicaid-paid community-based services, my daughter could not enjoy her home, and would not be contributing to her community as you and I do by shopping, paying rent and utilities and paying taxes in her home town.
Repeal cuts to Medicaid. SAVE HOME AND COMMUNITY BASED SERVICES.

Rene Cournoyer, Tacoma, Washington

Dear Members of the Special Committee on Aging,

Community living matters to me because it is so necessary to not only survive, but to thrive as a community. There is a city ordinance that states, if it gets colder than 46 degrees Fahrenheit, you need to bring your pets in or you will be fined. It was 39 degrees Fahrenheit last night and pouring rain. It is still pouring rain. There are people outside, as there are no shelters available, no spaces indoors in the day time either! Where is the humanity in government? A priest that I know performs memorials for the homeless. He has performed 981 this season, so far! Medicare and Medicaid are services that could have helped these folks. We are all so close to losing housing because of medical bills. That is what is happening all over America. Kiddos that were in foster care and have turned 18, are homeless. They have no money and no one is getting paid to house them any longer. They need to take care of themselves. Dentists and doctors are paid by Medicaid. Abused women and children flee beatings only to die in the bitter cold, hungry and cold. What God would want this for his people? Fascism sucks. Tax the Rich for the love of God. Israel has free college for all, free medical for all and we are sending them money so they can blowup Palestinians? How stupid and evil is America? We are the only country that has welfare that only helps the wealthy. Maga organization is a terrorist organization. We are all to be victims of the morally bankrupt rich. There is nothing radical about moral clarity.

Jessica Johnson, Freeland, Washington

Dear Members of the Special Committee on Aging,

I worked as a Medicaid personal care assistant and respite care provider for many years. My young, disabled clients needed help with all their ADLs and IADLs. With that help, they were

able to grow up and go to college or get jobs or move into supported living. And my life has been greatly enriched by getting to know them and helping them grow up into adults involved in their communities.

I was also a special education teacher until my own disabling health condition made it impossible to continue classroom teaching. Most of my former students will never live independently due to their developmental disabilities. In-home support enables them to live, and to have lives worth living, interacting with the world on their own terms, and being a boon to everyone lucky enough to know them.

Now I am medically disabled and my care is provided by my elderly parent. Obviously this is not a long term solution. The day will come when my parent is unable to provide my care, when we will both require caregivers. And when that day comes, I need to have access to the same supports I gave my clients and students. I have a life worth living, and I enrich the lives of those around me. I deserve to live with dignity, in a home of my choosing, and to have my basic needs met too.

Laura Waite, Redmond, Washington

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a widow age 62. My husband of 36 years died in 2021. He and I owned a small auto repair shop for 20 years and our biggest mistake was never preparing for our later years. We chose not to pay into Social Security because everyone said it would not exist when we needed it. We agreed to be responsible and save the money ourselves. Never happened. So now I am 62, I haven't worked since too many surgeries and too many sick days made me lose my job. On top of that I am going blind due to retinal deterioration. If it weren't for the support of my community and my children I would literally be living on the streets begging for my survival. Thanks to my community I can come and go as needed because of Metro and Hopelink. When my SNAP benefits were threatened last month I checked into alternatives and found that there are many sources for foodbanks. My community is prepared. I just pray that things don't get any worse before they get better.

Waldemar Itrich, Cashmere, Washington

Dear Members of the Special Committee on Aging,

I received a diagnosis of MS in 1974 but continued living my life as normally as possible. Then a friend suggested that I check into the local social services office where I was given information about doctors who turned me on to Medicare and Medicaid. Currently I'm learning about HCBS,

however this may answer that: I now abide in an excellent nursing home that provides my medical care. I suspect most if not all residents here fall into the same category as me: dependent on Medicare/Medicaid and praying that it won't be disappeared.

Tami Slack, Bellingham, Washington

Dear Members of the Special Committee on Aging,

Community living matters to me because without that I would not be able to participate in activities outside of my home I would be housebound. I struggle with depression. My only connection to the outside world would be through social media or FaceTime. this would be a severe impact in my life and not allow me the quality of life that other people could and do experience. Equity is a strong word these days removing these funds from this population is not equitable not fair and these folks deserve to live a life like any other person. we work and make contributions to the community on many different level's so we should also be able to receive the benefits of being in Community because we are part of that community. We work we play we interact with our community on many different levels please consider this plea and do not remove these services.

Rebecca Bisbee, Bellevue, Washington

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows me and my husband, both retirees, to still spend quality time with our 32-year-old daughter who has significant IDD while she lives in a home with professional caregivers and constant supervision. She continues to work and recreate in her community with her friends. It is a vital service for her well being and continuing care.

Christine Motokane, Sequim, Washington

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows me to be included in the community and keeps me from being isolated. Services provided by a Medicaid Home and Community based service waiver help provide services that allow me to live my best life. These services also provide respite and personal care for me as well.

If there are cuts to Medicaid Home and Community based services, I will be isolated at home and my parents who are my primary caregivers will have to take most of the burden. We need more funding for these waivers instead of cuts. Medicaid is more than health insurance for

disabled people like myself, they are a life line and helps me be more included in the community.

Allen Haydon, Tekoa, Washington

Dear Members of the Special Committee on Aging,

Community living matters to me because I live on SS and rely on Medicare and Medicaid for health care. Food stamps and the local Community Action Food Bank help me keep food on the table and my house warm and utilities on. I'm 81 years old. Three decades ago I was a CNA and worked as a Skills Trainer for developmentally disabled adults in Salem OR. The job opened my eyes to the true joy of being alive with or without a perfect mind and body. We must as humane creatures care for and sustain all living beings without exception otherwise our own lives are without much value.

Ibrahim Hafid, Lynnwood, Washington

Dear Members of the Special Committee on Aging,

Community living matters to me because I care

Rowena Donelson, Ferndale, Washington

Dear Members of the Special Committee on Aging,

Community living matters to me because my youngest brother, who is sixty-six and developmental disabled, has been living in community for twenty years. I am his guardian and am indebted to the people who care for him. Without 24/7 care he would not be able to function. With it he lives with three roommates who are also disabled. Each of them works outside the home, and enjoy social activities, but their interactions as friends is what gives the most satisfaction.

At eighty I am unable to care for my brother and frankly do not know how long I may be present in his life, but I am grateful that I know he will be secure in the future.

Please do everything necessary to support those who are aging or disabled.

Sincerely

Rowena M Donelson

Connie Grant, Clarkston, Washington

Dear Members of the Special Committee on Aging,

If Medicaid was taken away, I'd have 5 blood relatives on the streets, and several would die due to PTSD and mental health!

Cathy Petheram, Spokane Valley, Washington

Dear Members of the Special Committee on Aging,

I am a disabled 68 year old woman. If it wasn't for home care I would be stuck in an assisted living situation. A place where I can't have my dogs or garden.
My caregivers help me with many things, cooking, cleaning, bathing, dressing, Dr appointments and shopping.
Some days I do pretty good being able to dress myself, bathing, etc, but those days are few.
I live with chronic excruciating pain almost daily. I've now been bed ridden for two weeks in hopes that my lower left back n leg pain get better.
This home care and assisted living is mostly the only social interaction we have.
No one ever visits me unless I call my 1 friend for help.
We need hygiene supplies, laundry and other cleaning products that our insurance doesn't cover... We've worked our entire lives just to have our benefits consistently cut every year. It doesn't even ad up to the actual cost of living.
Thank you for taking the time to read this.

Jill Gilliom, Milton, Washington

Dear Members of the Special Committee on Aging,

Community living matters to me because I have an adult daughter who has autism and she depends on those services. She has a job, works 32 hours/week, lives in a supported home and receives job support services. She is an active member of her community and pays into social security. She doesn't get a large amount of support, but if that support goes away, her chances of becoming homeless will go up drastically. Her dad and I sought supported living services for her this year because we are 70 and desperately want to know that after we're gone she will be in a safe sustainable situation. Please don't jeopardize her long term life plan!

Corrine Anderson-Ketchmark, Des Moines, Washington

Dear Members of the Special Committee on Aging,

While I don't receive Medicaid, I know those who do and wouldn't have medical care without it.

Their health and quality of life would be greatly at risk without Medicaid. Their health cost of healthcare must be reduced significantly so that everyone can afford coverage!

Patricia Leinweber, Shoreline, Washington

Dear Members of the Special Committee on Aging,

My husband and I adopted our developmentally disabled daughter from the state of Washington when she was a baby. During her childhood, we asked for little help from the state, but now, as an adult, she relies on Medicaid home and community based services to fund a caregiver and an employment coach, as well as medical coverage, so that she can be as independent and productive as possible in her community. If she was without these services, she would be very alone when we die. It is the responsibility of the government to care for all of its citizens and to provide the means for life, liberty, and the pursuit of happiness. Developmentally disabled persons are citizens. Please provide for their needs.

Meghann Delaphlaine, Federal Way, Washington

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows people of all ages to access their community. It allows for essential therapy services, health and wellness, disability awareness for people needing home, as well as educational and transportation services.

Walter Abplanalp, Ethel, Washington

Dear Members of the Special Committee on Aging,

Community living matters to me because our 40 yr old daughter lives with Autism. She needs care and she needs Medicare to fill in the gaps to pay those costs.

Matthew McDonald, Seattle, Washington

Dear Members of the Special Committee on Aging,

Community living matters to me because I have autism and what if I can't find a job prior to running out of money?

Walter Abplanalp, Ethel, Washington

Dear Members of the Special Committee on Aging,

Community living matters to me because our daughter also has Medicaid and needs it to fill in the gaps

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Leon Robert, Seattle, Washington

Dear Members of the Special Committee on Aging,

Community living matters to me because recently widowed Medicaid was there for me during a health crisis.

Casey Forsyth, Olympia, Washington

Dear Members of the Special Committee on Aging,

Community living matters to me because my son Ian has been receiving community services since he was 15yo, he is currently 37. During Covid these services were limited and I noticed that he wasn't eating or bathing on a regular schedule and he was upset and angry a lot. I am his primary caregiver and he relies on these services for support to be able to survive.

Cathy Hickman, Ellensburg, Washington

Dear Members of the Special Committee on Aging,

Community living matters to me because

Hello, I have an adult son with Autism.
He has Diabetes and high cholesterol.

He needs Medicare for his medication and doctor appointments and bloodwork!

It is of upmost importance he receives the medical care he has been receiving!

Please Do Not Take this life saving coverage away!

Thank You for taking your time reading this letter!

Sincerely, his Mom, Cathy

U.S. Senate Special Committee on Aging

"Aging in Place: The Impact of Community During the Holidays"

December 3, 2025

Statements for the Record

Statements from West Virginia

Ryan McKinley, Shepherdstown, West Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because I can live with my mother and we help each other. We share cooking, house cleaning, yard work, and animal care. My anxiety and depression are less having her around and helping me face my daily challenges. I'm also Autistic and she helps me by managing my Medicaid, SSI and food stamps. She is also retired and my rent payments help both of us have a home to live in.

Pamela Johnson, Charleston, West Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because human beings deserve resp

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Brandi Gunnoe, Madison, West Virginia

Dear Members of the Special Committee on Aging,

I am a person with disabilities and have been assisted my DRS services in obtaining my RN degree. My pinning is in a few weeks and this would never have been possible without programs like these. Now my husband and I will not have to spend our entire existence living off these programs and can actually LIVE instead of merely survive. That's what generally what these things allow most people to do ...survive....so without them, their survival rate would decline, not to mention their quality of life! Please do not take these programs away. I am proof that they can be utilized to improve your life permanently and should continue to be available to those who can follow the rules and lean instead of depend. Thank you! God Bless!

William Mcyoung, Apple Grove, West Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because I have been living in a tent. 64 with painful p.v.. when it got in the 20's it was rough folks figured I will freeze to death... I need help.

Tiffany Love, West Virginia

Dear Members of Congress,

I am writing to urge you to continue protecting and strengthening Medicaid Home and Community-Based Services (HCBS) and Medicaid waiver programs. These programs are not only life-changing for individuals with disabilities and their families—they are also fiscally responsible, humane, and essential to ensuring safety, independence, and quality of life.

My daughter is one of the many Americans whose life has been transformed by HCBS. When she first began receiving home-based waiver services, she was completely nonverbal. Through access to speech therapy, occupational therapy, physical therapy, and communication-technology supports—services our family could never have afforded without Medicaid—she has made tremendous progress. She has learned to communicate using a device, she self-teaches in multiple languages, she swims, rides a bicycle, and expresses her love for music. These milestones were only possible because she is able to receive consistent, qualified care in the safety and comfort of her home.

As her full-time caregiver, I am unable to work. Her needs require 24/7 care, supervision, and support. Without Medicaid waiver services, my daughter would have no option but to enter an assisted living or institutional care facility. Such placement would cost the state millions of dollars over her lifetime—far more than the cost of providing home-based services. HCBS allows families like mine to provide safe, loving, personalized care at a fraction of what institutional care requires. It is both the compassionate and financially prudent approach.

In addition to the financial benefits, HCBS protects disabled individuals from the significant risks associated with institutional settings. Reports of abuse and neglect in care facilities across the country are well-documented. My daughter is nonverbal and would not be able to report mistreatment. In a facility, she could easily lose the skills and progress she has worked so hard to gain—progress she would likely never regain. Her safety, well-being, and development depend on her ability to remain at home with people who love her.

Medicaid waiver programs promote independence, dignity, and meaningful community involvement. They give disabled individuals a chance to thrive, learn, grow, and one day potentially live more independent lives. Eliminating or weakening these programs would not only endanger countless families, but would also lead to far higher long-term costs for states and the federal government.

I am asking you—on behalf of my daughter and thousands of families like mine—to protect and expand Medicaid home-based services. These programs are not optional; they are vital lifelines. They keep vulnerable individuals safe, support family-based caregiving, reduce institutional reliance, and ensure that people with disabilities can live full and meaningful lives in their own communities.

Please do not eliminate or reduce funding for Medicaid HCBS or waiver programs. Our family, and so many others across this country, depend on these essential services.

Thank you for your time, your compassion, and your commitment to supporting families and individuals with disabilities.

Sincerely,
Tiffany Love
Re/: my daughter, Audrey "Bella" Love

Jean Mullins, Pigeon, West Virginia

Dear Members of the Special Committee on Aging,

Community living matters to me because, my Father in law is elderly and disabled. Without Medicare he wouldn't have great Healthcare, he wouldn't be able to age in place!
I couldn't imagine having to put him onto a nursing home, he grew up in the country, lived his entire life on a farm, now then he became disabled , he was still able to stay on his farm because of Medicaid, his medical needs were met, and his son helped him, along with many family members.
Now he is elderly, sold his farm, and lives in a trailer near us, his health care is taken care of and since he doesn't have to pay for insurance his social security goes towards his groceries and any other needs he has....please continue disability services!

U.S. Senate Special Committee on Aging

"Aging in Place: The Impact of Community During the Holidays"

December 3, 2025

Statements for the Record

Statements from Wisconsin

Christopher Rates, Winnebago, Wisconsin

Dear Members of the Special Committee on Aging,

Community living matters to me because my son has Down Syndrome. While he is young now, every support he has had to make him more independent and more able to succeed like the other kids in his class has made an incredible impact on his development and his happiness. I hope when he is older there will still be programs that allow him to participate in his community, attend school and work, and support him. It makes all the world to people like my son and the exhausted family members who do everything we can. But we can't do it without support through HCBS and Medicaid. Thank you for reading this.

Laurine Lusk, Belleville, Wisconsin

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a 45 year old daughter who has autism, intellectual disability and physical disability. Throughout her 21 years of schooling, her rights were continually violated and our family had to hire tutors, attorney's, file complaints with the department of education, and move three times trying to get her better services. Our income was severely impacted due to those in the public school system not following the federal and state laws. After all of her hard work, and our family's sacrifices, she owns a condo on the west side of Madison and continues to work two part time jobs that she's held for over 25 years. She lives far below the poverty line, relying on funds from my husband and me, and relying on Medicaid to pay her support team of workers who provide 55 hours per week. That support team helps drive her to/from her 2 jobs, wash her hair, plan and prepare her meals, balance her very tight budget, get her doctor and therapy appointments, and take her to the fitness center so she can remain strong enough to tolerate being on her feet at work. I volunteer around 15 hours per week recruiting, training and supervising her 5 staff and I fill in when staff can't cover a shift. I have no idea who will provide that much free support and extra funds when I die. I'm 74 now, and the stress has taken a great toll on my memory and physical functioning.

If you make any cut to Medicaid, no matter how small, we will likely lose staff because they are already grossly underpaid. I don't have the energy or skills to fill in or any more time than I'm already providing. Megan will likely need to quit her two jobs, give up her condo, and move in with me, in a neighboring city. You will be destroying a very fragile system of support that is already based upon too low of wages to recruit and keep support staff for more than a few months before they quit and I need to try recruiting again. The research is there; you and all of us know that community living is far less expensive than institutional living (1/10th the cost). So, I imagine that if you cut medicaid you are actually aiming to kill the millions of people with disabilities who have aging parents who can't help them OR who have no parents alive and able

to take over. You will be forcing people with disabilities to live on the streets, where the current president will round them up and put them in holding centers with no health care and little food and water. You will be murderers. We see you. We see your goals. Our family and my daughter have been paying taxes our entire lives. We aren't cheaters, like the Republicans in Congress who have been making millions off the stock market ups and downs, designed by the president's game with tariffs. We know what you are doing. If you cut one dollar of Medicaid, you will be murdering your own constituents. Shame on you for even considering this, along with SNAP cuts, along with destruction of USAID, along with cuts to OSEP, along a tax system that allows billionaires to pay NOTHING. If you kill more vulnerable people, I pray that you will will be replaced, then tried and convicted, then spend your life in prison, then pay your dues when you are judged by God.

Diana Lewis, Oconomowoc, Wisconsin

Dear Members of the Special Committee on Aging,

Community living matters to me because my husband and I live on Medicare as does my special needs niece and nephew!

Roger Schmidt, Madison, Wisconsin

Dear Members of the Special Committee on Aging,

Community living matters to me because we must all work together and learn togeather and make things better for all!

Tanya Roberts, Oshkosh, Wisconsin

Dear Members of the Special Committee on Aging,

Community living matters to me because, I was able to live on my own, in the city, then i had more seizures. I moved back in with my parents I am now looking for a new place, if it wasn't for medicaid i would not be able to afford my medication to keep my epilepsy under control, I also have more medications. Medicaid HBCS, will help me get and stay living independently.

Jordan Anderson, Auburndale, Wisconsin

Dear Members of the Special Committee on Aging,

Hello, my name is Jordan. I have some issues typing so if you guys could get in touch with me,

but I have a story that I would like to share, but I wanna make sure I capture everything that you would like me to.

Thank you

Kristi Schuenemann, Watertown, Wisconsin

Dear Members of the Special Committee on Aging,

For myself, and millions of others with disabilities, living in our communities is everything!! If I am not able to live in my community that would mean giving up all of the activities I'm involved in; most of which are rooted in disability advocacy. Being able to live in my community gives me friends, freedom and access to local events. Just today I was able to attend a meeting at my local senior center to talk about fundraising opportunities for an inclusive park being built in my town. I also was able to be part of a promotional video for the park. Programs like Medicaid HCBS have been vital in helping me get accessible housing at an apartment complex in my town. Before moving out to my own place I was restricted in where I could go on my own and my interactions were largely through email/social media. There are still accessibility issues with a large portion of buildings in my area, but now living near downtown I am able to explore more. Please don't take away my freedom and right to be an active member of my community. Thank you!

John Hien, St. Francis, Wisconsin

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm a disabled veteran. Currently an employee, Bonnie, here at Howard Village (a Sinceri senior apartment complex) is protesting the living conditions of veterans living here. The manager, Matt Fischer, conducts himself as if he were a king. In my case, I was in the hospital for 14 days. According to my lease, after 7 days I was entitled to a refund for meals I missed. Mr. Fischer denied my refund request until a Sinceri corporate executive intervened. I was finally given the refund.

Karen OBrien, Kenosha, Washington

Dear Members of the Special Committee on Aging,

Community living matters to me because the disabled U.S. military veterans I serve at my American Legion Post 21 in Kenosha, Wisconsin, deserve care and continue to give back to the community as they are cared for.

Chris Chatham, Eau Claire, Wisconsin

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps many people who without would be unable to get the help and care they need.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Wyoming

Julie Bird, Riverton, Wyoming

Dear Members of the Special Committee on Aging,

Community living matters to me because, the elderly and disabled people like me that can't work and only have a small social security to live on deserve everything possible I can get to survive and with the cost of living these days every little thing helps. Don't understand why the elderly and disabled keep losing everything like their benefits and health insurance and they pay more for things like healthcare.

Susan, Krause, Cheyenne, Wyoming

Dear Members of the Special Committee on Aging,

Community living matters to me because my community is thriving and full of good people.

U.S. SENATE SPECIAL COMMITTEE ON AGING

"AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS"

DECEMBER 3, 2025

STATEMENTS FOR THE RECORD

Statements from Organizations, Nonprofits, and Providers



The Kelsey

1 Sansome Street, Suite 1451
San Francisco, CA, 94104
thekelsey.org

Re: Statement for the Record, December 3rd, 2025 Hearing on Aging in Place: The Impact of Community during the Holidays

December 8, 2025

Dear Chairman Scott, Ranking Member Gillibrand, and Members of the Committee:

Thank you for the opportunity to submit testimony. We, at The Kelsey, submit this statement as a national affordable housing developer, technical assistance provider, and advocacy organization that advances affordable, accessible, integrated, and inclusive housing for people with and without disabilities. We would like to highlight the essential role of Medicaid Home and Community-Based Services (HCBS) and Centers for Independent Living (CILs), and how such programs are a necessity in upholding the promise of community living and creating a housing future where everyone thrives.

Housing as the Foundation of Community Living

Community living is not possible without housing—and not just any housing, but homes that people can *afford*, *access*, and *choose* in the communities where they want to live. For the nation's more than 70 million disabled people, housing barriers remain profound: too few affordable homes, too few accessible options, and too few options free from discrimination. Our mainstream housing infrastructure continues to isolate disabled people from their communities of choice, supports, and other opportunities.

The consequences are clear. Disabled people experience the highest rates of housing discrimination, disproportionate housing cost-burden, and continued institutionalization, and disproportionately high rates of homelessness and housing insecurity. Testimony we have previously submitted to this Committee underscored these dynamics and their impacts on older adults and disabled people seeking to live in the community.

The Committee's attention to community living is urgently needed, because community living is only possible when affordable, accessible, and inclusive housing is paired with in-home and community-based services and supported by durable community infrastructure—including CILs—that enable disabled people and older adults to thrive.

HCBS as a Pillar of Disability-Forward Housing

The Kelsey

1 Sansome Street, Suite 1451
San Francisco, CA, 94104
thekelsey.org

Medicaid HCBS programs are core to enabling disabled people and aging adults to live outside institutions. More than 5.1 million people rely on HCBS, with approximately 606,895 people waiting for Medicaid home care. Without these supports—ranging from personal care and behavioral supports to tenancy stabilization—many individuals simply cannot maintain housing in the community.

We provide a decoupled approach to housing and services. Residents choose their own HCBS providers; this choice is protected by law and critical to self-determination. However, housing providers must play a crucial role in coordinating and facilitating access—helping residents connect to the proper supports, ensuring people understand their options, and ensuring that buildings are physically and operationally designed for cross-disability access.

At The Kelsey, we see this every day. Across our communities—including The Kelsey Ayer Station in San Jose and The Kelsey Civic Center in San Francisco—residents with and without disabilities live side-by-side, with on-site staff connecting residents to HCBS providers, community-based supports, and peer networks that cultivate belonging and ensure housing stability. In Birmingham, Alabama, where we are finalizing financing for another inclusive housing community, people with and without disabilities are eagerly awaiting the availability of what will be The Kelsey Avondale.

As we continue to develop our own housing communities and partner with inclusive housers who are doing the same, federal resources are finite compared to the need, leaving millions of disabled people and their families who do not have service-ready, affordable, accessible housing options.

Without robust HCBS funding, including but not limited to housing-related services, direct support professionals, and community-based transition services, inclusive housing models would not be possible.

The Essential Role of Centers for Independent Living

Centers for Independent Living are invaluable partners in promoting housing stability, providing transition services, and facilitating community living. At The Kelsey, CILs serve as critical referral partners—identifying eligible residents, supporting application processes, and ensuring residents have the independent living supports they need to succeed in community-based settings. CILs ensure a growing referral pipeline beyond

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1 Sansome Street, Suite 1451
San Francisco, CA, 94104
thekelsey.org

just homelessness providers to ensure that there are organizations supporting people who are transitioning from nursing homes, group homes, and other institutional settings.

Beyond referral partnerships, CILs are critical partners in our community engagement efforts for future housing developments and as partners in local, state, and national advocacy efforts.

Congressional investment in CILs and all programs that support disabled people to lead and live their own lives in the communities of their choice is not only an investment in community living but in the success and sustainability of an inclusive housing future where everyone lives and ages in place.

The Imperative for Federal Leadership

Congress has significant authority—and responsibility—to expand community living opportunities. Federal leadership is essential to:

Strengthen and Expand HCBS

- Increase mandatory and optional HCBS funding to eliminate waitlists.
- Stabilize and raise wages for direct support professionals.
- Sustain and expand Money Follows the Person.
- Encourage Medicaid–housing partnerships that support tenancy, transition, and community integration.

Invest in Affordable, Accessible, Integrated Housing

- Sustain and expand the Department of Housing & Urban Development's (HUD) Section 811 Program.
- Protect and increase HUD's Housing Choice Vouchers, including Mainstream Vouchers and Non-Elderly Disabled Vouchers for adults with disabilities.
- Modernize the Low-Income Housing Tax Credit (LIHTC) with accessibility and inclusion incentives, such as those described in the 118th Congress Senate Bill 1377 - Visitable Inclusive Tax credits for Accessible Living (VITAL) Act.
- Fully align federal housing programs with the civil rights and fair housing protections.

Support Centers for Independent Living

- Increase operational and programmatic funding for CILs.

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1 Sansome Street, Suite 1451
San Francisco, CA, 94104
thekelsey.org

- Expand federal support for transition and diversion services from institutional settings.
- Promote CIL participation as core referral partners in federal housing and services programs.

Conclusion

Community living is not solely a matter of services, nor solely a matter of housing—it requires both, and it requires them to work together in ways that respect autonomy, dignity, and civil rights.

HCBS enables people to live where they choose. CILs equip people with the tools and support to thrive. Affordable, accessible, inclusive housing provides the foundation for both.

Congress has a profound responsibility—and a profound opportunity—to uphold the rights established under the ADA and *Olmstead* and to make the promise of community living real for millions of disabled people and older adults.

By robustly investing in HCBS, strengthening CILs, and dramatically expanding the supply of affordable, accessible, and integrated housing, Congress can ensure a future where all people have a home and a community in which they can belong, contribute, and flourish.

Thank you for your leadership and for your continued commitment to advancing community living nationwide. We are available to partner in advancing this policy agenda.

Sincerely,

Allie Cannington
Managing Director
The Kelsey
allie@thekelsey.org



U.S. Senate Special Committee on Aging
Aging in Place: The Impact of Community During the Holidays
Wednesday, December 3, 2025

The American Network of Community Options and Resources (ANCOR) appreciates the opportunity to submit a statement for this hearing, *Aging in Place: The Impact of Community During the Holidays*. We appreciate this committee's focus on the importance of community living and urge the committee to support policies to invest in and strengthen community-based services for people with intellectual and developmental disabilities (I/DD).

Founded 55 years ago, ANCOR is a national, nonprofit association representing more than 2,500 private, mostly non-profit community providers of long-term supports and services to people with I/DD, as well as nearly 60 state provider associations. Combined, our members support more than one million individuals with I/DD in all 50 states across their lifespan and are funded almost exclusively by Medicaid. Our mission is to advance the ability of our members to support people with I/DD to fully participate in their communities.

Community-Based Services Benefit Individuals with I/DD

Medicaid-funded community-based services are a lifeline for people with disabilities. ANCOR's members offer a broad range of supports to help people with I/DD live full and independent lives in their homes and communities. Through Medicaid-funded community-based services, people with I/DD have access to a spectrum of person-centered supports, including assistance with activities of daily living, skill-building supports, community integration, and employment opportunities. These supports enable people with I/DD to develop a greater level of independence and autonomy and contribute meaningfully to their communities.

Community-based services also honor individuals' and their families' choices for those who choose to remain in their homes and communities, rather than large institutional settings. Moreover, there is abundant empirical evidence that people with I/DD lead happier, healthier, and more productive lives in community-based settings with opportunities to make choices about their lives. This research indicates that:

- People who move from state-operated public institutions to smaller community homes are happier, healthier, have more control over their lives, and are better able to function more

independently after they move.[1]

- Individuals moving from large institutions to community settings consistently develop their daily living skills to a higher level than their peers who remain institutionalized.[2]
- People with disabilities have more opportunities to exercise choice over their lives when residing in community settings and such opportunities are associated with positive outcomes and a higher quality of life.[3]

Community inclusion—the ability to live and engage in the community just like everyone else—leads to improvements in a person's overall health and well-being. Unfortunately, individuals with disabilities are twice as likely as other populations to experience social isolation and loneliness.[4] This only underscores the importance of supporting community-based services. For more on the importance of community-based services, see Stories Collected from ANCOR's Provider Network.

Community-Based Services Benefit Families, Communities, and Local Economies

In addition to improving individuals' health and well-being, Medicaid-funded community-based services enable individuals with I/DD to receive support outside of family caregivers. Providing support options for people with disabilities enables family caregivers to remain in the workforce and continue to earn wages. Without the option to maintain employment, family members lose thousands of dollars annually in unearned wages[5] and face mounting out-of-pocket expenses and the physical and emotional strain of caregiving, leading family caregivers to be more likely to need additional support through public assistance.

These services benefit communities in a myriad of ways. Community providers of I/DD services support a robust economy as employers of one of the fastest growing workforces, as well as providers of employment support services for people with disabilities. The direct impact of employing thousands of individuals as direct support professionals as well as the indirect impact of those employees' economic output in their local communities produces positive outcomes at the state level. For example, a recent study of New York state disability services found that the economic impact was double the investment the state disability agency made into those services—an investment of $6.7 billion into disability service providers led to $14.3 billion in economic activity.[6]

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[1] Sheryl Larson et al., *Behavioral Outcomes of Moving from Institutional to Community Living for People with Intellectual and Developmental Disabilities: U.S. Studies from 1977 to 2010,* Research and Practice for Persons with Severe Disabilities (2013), *available at* https://journals.sagepub.com/doi/10.2511/027494813805327287.

[2] National Association of State Directors of Developmental Disability Services & Association of University Centers on Disabilities, *The Effects of Community vs. Institutional Living on the Daily Living Skills of Persons with Developmental Disabilities* (2011), *available at* http://www.evidence-basedpolicy.org/docs/evidence-based_policy.pdf.

[3] Katherine M. Burke et al., *Self-Determination Research: Current and Future Directions*, Behavioral Sciences (2024), *available at* https://doi.org/10.3390/bs14070613

[4] Glenda M. Bishop et al., *Disability-Related Inequalities in the Prevalence of Loneliness Across the Lifespan: Trends from Australia, 2003 to 2020,* BMC Public Health (2024), *available at* https://doi.org/10.1186/s12889-024-17936-w.

[5] *Families Caring for an Aging America*, National Academy of Sciences (2016), https://www.ncbi.nlm.nih.gov/books/NBK396402/.

[6] Laura Schultz, *The Role of Disability Service Providers in the New York State Economy* (2021), *available at* https://rockinst.org/wp-content/uploads/2021/12/the-role-of-disability-service-providers-in-the-new-york-state-

Additionally, community providers support individuals with disabilities to gain and retain employment through job coaching and employment supports to help them enter and stay in the workforce. And in doing so, help individuals with I/DD gain further independence through employment, better enabling them to contribute economically to their communities.

Medicaid home and community-based services are also a cost-efficient solution as compared to the alternative of providing long-term supports in a nursing facility or large state-run institution. Medicaid home- and community-based services are far less costly for states than long-term services and supports rendered in institutional settings. The average annual per capita cost to serve someone with I/DD though a home and community-based waiver program is $49,764 while the projected cost to serve that individual within a large state-run institution would be $325,580[7] and the average per capita cost to support someone with a mandatory service, such as in a nursing facility, is $111,325.[8] Investing in community-based supports also enables states to ensure individuals receive the supports they need and can avoid more costly services like hospital or emergency care services down the line.

Congressional Support Is Necessary to Ensure the Sustainability of Community-Based Services

Even with data supporting the need for community-based services for people with I/DD, these services are in a fragile state. ANCOR recently conducted its sixth-annual survey of community providers, and the findings indicate that 88% of providers report experiencing moderate or severe staffing challenges in the past year, resulting in 62% of providers turning away new referrals and 52% of providers considering further cuts to programs.[9] Now, providers are concerned about the impact of recently passed legislation that places limitations on state and federal funding for Medicaid and how it might further exacerbate the already fragile state of Medicaid community-based services and lead to decreased access to services.

Across the country, more than 500,000 people with I/DD are already on states' waiting lists for home- and community-based services.[10] Wait times are often several years to decades long, forcing people with disabilities to either go without the support they need or be forced into hospital emergency rooms, nursing homes, and large high-cost state-run institutions. Service reductions resulting from the ongoing workforce shortage and pending Medicaid cuts will only grow these years-long waiting lists, putting community supports for people with disabilities out of reach for thousands of families, and

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economy.pdf.

[7] Residential Information Systems Project, *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities* (2020), *available at* https://icis.umn.edu/files/a6fkEiad6J/2020_risp_report?preferredLocale=en-US.

[8] American Council on Aging, *2024 Nursing Home Costs by State and Region* (2025), https://www.medicaidplanningassistance.org/nursing-home-costs/.

[9] American Network of Community Options and Resources, *The State of America's Direct Support Workforce Crisis 2025*, https://www.ancor.org/wp-content/uploads/2025/10/The-State-of-Americas-Direct-Support-Workforce-Crisis-2025.pdf.

[10] Kaiser Family Foundation, *Number of People Waiting for Medicaid Home Care (HCBS), by Target Population and Whether States Screen for Eligibility* (2024), kff.org/medicaid/state-indicator/number-of-people-waiting-for-hcbs-by-target-population-and-whether-states-screen-for-eligibility/.

raising unnecessary costs for states to cover health care in more expensive settings.

To ensure a sustainable system and keep the promise of community living for people with I/DD a reality, Congress must support and invest in community-based services. The data is clear that increased federal investments help to strengthen and sustain community-based services. Recently, temporary federal investments into the Medicaid Home and Community-Based Services (HCBS) program were authorized through the American Resue Plan Act (ARPA). This funding was instrumental for states in strengthening their community-based services, with every state and the District of Columbia utilizing ARPA funding to invest in strengthening their direct support workforce. ANCOR's annual provider survey demonstrates that during this time period, even though community-based providers continued to experience workforce staffing shortfalls, fewer providers indicated they were closing programs or services.[11] For example, in 2022, 63% of survey respondents reported closing programs or services. After the release of additional federal funding through ARPA, that figure dropped to 44% in 2023, decreasing to 39% in 2024, and down to 29% in 2025.[12]

Congressional support for legislation that will bolster community-based services is necessary for the sustainability of these services. We ask for support for the HCBS Relief Act (S. 2076), which would provide an enhanced federal match for states to invest in their Medicaid Home and Community Based Services programs. We also urge support for the Recognizing the Role of Direct Support Professionals Act (S.3211), which would help create a standard occupational classification for direct support professionals, enabling accurate data collection on the direct support workforce.

Our communities are at their best when all people, including people with disabilities, have the opportunity to develop skills, achieve greater independence, and successfully reach their goals. Sufficient Medicaid funding and a robust community provider network are foundational to building a stronger America for everyone. The best way to keep health care affordable, sustainable, and available for the individuals with I/DD who depend on it is to invest in community-based services.

For questions or more information, please reach out to Elise Aguilar, Senior Director of Federal Relations, at eaguilar@ancor.org.

Sincerely,

Barbara Merrill
Chief Executive Officer ANCOR

[11] American Network of Community Options and Resources, *The State of America's Direct Support Workforce Crisis 2025*, https://www.ancor.org/wp-content/uploads/2025/10/The-State-of-Americas-Direct-Support-Workforce-Crisis-2025.pdf.
[12] *Id.*

AARP
STATEMENT FOR THE RECORD
for the

U.S. SENATE SPECIAL COMMITTEE ON AGING
on

AGING IN PLACE: THE IMPACT OF COMMUNITY DURING THE HOLIDAYS

December 3, 2025
Washington, DC

For further information contact:
Rhonda Richards
Government Affairs Director
Family and Caregiving
rrichards@aarp.org

AARP, on behalf of 125 million Americans age 50 and older and their families, thanks the Committee for holding this hearing, "Aging in Place: The Impact of Community during the Holidays." We appreciate the opportunity to submit this statement for the record on the importance of helping older adults and people with disabilities live independently in their homes and communities. This includes supporting family caregivers who make this possible and ensuring access to essential services through Medicaid and the Older Americans Act (OAA).

According to AARP's 2024 Home and Community Preferences Survey, the vast majority of Americans age 50-plus would like to live in their current home (75 percent) and community (73 percent) for as long as possible. People want to be near family, friends, social connections, and community they know and enjoy being part of – this increases their quality of life, independence, and personal fulfillment.

Family Caregiving
There are 63 million family caregivers in the United States caring for adults or children with a medical condition or disability, enabling people to live in their homes and communities where they want to be. Family caregivers help with everything including medications and medical care, meals, bathing, dressing, finances, grocery shopping, transportation, coordinating and arranging care, advocating on behalf of their loved one, and more.

While many find purpose in caregiving, it often brings financial, physical, and emotional challenges. Family caregivers spend, on average, over $7,200 on out-of-pocket caregiving expenses each year, which equates to about 25 percent of their income on average. Nearly half experience at least one negative financial impact, such as depleted short-term savings, increased debt, unpaid bills, borrowing money, or struggling to afford basics like food. Seven in ten caregivers ages 18-64 are working while caregiving. Many reduce hours or leave the workforce, losing income, benefits, and retirement savings. The financial and economic toll are significant.

Family caregivers provide billions in unpaid labor annually, reducing costly institutional care, hospitalizations, and emergency room visits, saving taxpayer dollars. On average, caregivers provide 27 hours of care per week. Nearly one-third of caregivers care for an adult with disabilities or complex medical conditions and a child under 18 at home. Over half (58 percent) of family caregivers act as an advocate on behalf of their loved one. One in four want help managing paperwork and navigating eligibility for services. Among those coordinating care, 26 percent find it difficult to do so.

Family caregivers need commonsense solutions to help save them money, time, and provide them with support. That's why AARP urges Congress to pass the:

- Credit for Caring Act (S. 925) that would provide a non-refundable federal tax credit of up to $5,000 for eligible working family caregivers to help offset a portion of out-of-pocket caregiving expenses such as a home care aide, home modifications, assistive technology, adult day services, respite care, transportation and other supports that help caregivers and their loved ones;

- Lowering Costs for Caregivers Act (S. 1565) that would allow family caregivers to use their health savings accounts, flexible spending accounts, health reimbursement accounts, and Archer medical savings accounts to pay for qualified medical expenses for their parents or parents-in-law, and not just spouses or dependents;

- Alleviating Barriers for Caregivers Act (S. 1227) that would help reduce red tape for family caregivers in Medicare, Medicaid, Social Security programs, and the Children's Health Insurance Program;

- Lifespan Respite Care Reauthorization Act (S. 830) to reauthorize the Lifespan Respite Care Program through Fiscal Year 2030 and enable the program to serve caregivers under age 18, helping to ensure access to respite care to give caregivers short breaks from their caregiving responsibilities; and

- the Connecting Caregivers to Medicare Act (to be reintroduced) that would help inform people about Medicare's voluntary option for Medicare beneficiaries to allow family caregivers to access their health information through 1-800-MEDICARE.

Administrative actions are also important and can support family caregivers. The Centers for Medicare & Medicaid Services (CMS) under the Medicare Physician Fee Schedule pays some health care professionals to provide Caregiver Training Services (CTS) to help train family caregivers in providing different types of care or assistance to a person with Medicare. In the 2026 Medicare Physician Fee Schedule final rule, CMS made it permanent for CTS to be delivered through telehealth. This change means family caregivers can access these important services more easily. This matters because only 11% of caregivers get any formal training to help with daily tasks like bathing or dressing (activities of daily living, ADLs) or preparing meals or handling transportation (instrumental activities of daily living, IADLs). Yet two-thirds of caregivers help with at least one ADL. And while most caregivers handle medical or nursing tasks, only 22% receive training for them. Expanding CTS—especially through telehealth—is a key way to make sure family caregivers get the training and support they need.

The Guiding an Improved Dementia Experience (GUIDE) Model under the CMS Innovation Center provides essential support for family caregivers of Medicare beneficiaries with dementia, including 24/7 access to a support line, caregiver navigation, caregiver education and training, and respite care. The GUIDE Model serves as a strong example to build upon. We have called on CMS—especially within Medicare—to consistently recognize the essential role family caregivers play in care planning, treatment, transitions (including discharge), and coordination. CMS should support caregivers by formally including them as vital members of the care team, offering education, training, navigation assistance, respite care, and other supports, and ensuring that caregivers receive support across traditional Medicare, Medicare Advantage, and any CMMI care model. CMS replication and scaling of successful models are also important.

CMS should take steps to exempt family caregivers —defined in Section 2 of the RAISE Family Caregivers Act —from Medicaid's community engagement requirements. This would enable caregivers to continue to provide essential care to loved ones that helps them live independently in their homes and allows the caregiver to continue to receive health care coverage through

Medicaid. Family caregivers are already saving taxpayer dollars by caring for their loved ones at home and delaying and preventing more costly institutional care and unnecessary hospital stays.

We look forward to continuing to work with Congress to advance policies that recognize the vital role caregivers play within our families and the long-term care system. The holidays and getting together with family and friends often provide time for future or current family caregivers to observe that a family member or friend may need more help with daily activities than they did previously.

Older Americans Act
Family caregivers are often the first line of assistance for a loved one who needs help living in their home. But some individuals needing assistance may not have a family caregiver or one able to help, or they may need more help than family caregivers can provide. They may pay out-of-pocket for services or rely on programs, such as the Older Americans Act (OAA), to meet their needs or fill in critical gaps.

For 60 years, the OAA has helped older Americans live at home with independence and dignity, deferring or eliminating more costly institutional services and hospitalizations. It delivers essential services to approximately 11 million older adults in a typical year, including home care, job training and employment opportunities, family caregiver support, congregate and home-delivered meals, case management, transportation, adult day care, legal services, elder abuse prevention, and long-term care ombudsman programs to help keep people safe. OAA programs are cost-effective investments that serve the needs of older Americans while helping them to remain in their homes and communities as they age, where the vast majority prefer to be. America's older population is growing and so too must the resources to help them remain independent and live at home. Now more than ever, OAA programs are essential for America's older adults and their families.

AARP supports the Older Americans Act (OAA) Reauthorization Act of 2025 (S. 2120). AARP commends you for your bipartisan work on this legislation and joins you in calling for its prompt passage. Within the OAA Reauthorization Act of 2025, we appreciate and support the effort to strengthen OAA's many successful programs, including the National Family Caregiver Support Program (NFCSP) and Title VI Native American Caregiver Support Services, the Senior Community Service Employment Program (SCSEP), nutrition services, the Long-term Care Ombudsman Program (LTCOP), the direct care workforce national resource center, and housing services. AARP recently provided a more specific statement for the record on OAA, that highlights the important services it provides, and the need to promptly reauthorize OAA so that our loved ones can continue to turn to these services for their health and economic security as they age.

Medicaid Home and Community-Based Services
After individuals receive help from family and friends, spend through their savings to pay out-of-pocket for care, use OAA programs or other public programs, they may turn to Medicaid as an essential safety net to help them live at home and in the community. Several million adults 50-plus, including more than 2 million people ages 65 and over, are enrolled in Medicaid because they have significant disabilities or functional limitations that require hands-on assistance. While

more than 2.3 million adults 65 and older and 3.8 million adults ages 21 to 64 (many of whom are 50 and older) receive Medicaid coverage for long-term care, almost two-thirds of adults 65 and older with Medicaid long-term care coverage receive home and community-based services (HCBS), including from home care aides. More than 1.5 million older adults received Medicaid HCBS in 2022, with older adults making up about one in five Medicaid HCBS recipients. Overall, more than 9 million people of all ages receive Medicaid long-term care, including 7.8 million people who receive HCBS.

Medicaid provides essential services such as a home care aide, adult day services, personal care, and more, but also support for family caregivers, such as respite care and education and training. The important services Medicaid provides can also fill in gaps in care that families may not be able to meet and can make the difference between a person being able to live in their home or having to go into a nursing home.

Federal law requires states to cover institutional care, such nursing home care. However, most HCBS are optional, giving states discretion to change what services are covered, eligibility for them, or payments to providers which can impact access to services, even though HCBS are generally more cost-effective. Medicaid HCBS costs an average of almost $25,900 per older adult, and Medicaid spends on average about $20,000 less per year per older adult who receives HCBS rather than nursing home care. Addressing long-term care should involve reforms to remove Medicaid's bias toward institutional care and increase support for families who take care of their loved ones at home. As recent changes to Medicaid are implemented, it will be important for the federal government and states to protect against cuts to home care or HCBS that make it harder for older adults and people with disabilities to live in their homes and communities. Such cuts could lead to less preferred care in nursing homes that is more costly for individuals and taxpayers.

It is important for Congress in the next couple of years to make permanent or at least extend:

- The Money Follows the Person Rebalancing Demonstration Program that helps individuals transition out of institutional settings to certain home and community-based settings and

- Medicaid HCBS spousal impoverishment provisions that provide important financial protection for the spouses of individuals receiving Medicaid HCBS.

Without action by Congress, both will expire September 30, 2027. These are important provisions that help address Medicaid's institutional bias.

We support bolstering the paid direct care workforce who provides essential assistance with daily activities that help people remain in their homes and get the support they need regardless of where they reside. While the demand for this workforce is high, the job quality (including wages) is low, which contributes to high turnover and workforce shortages. Helping to ensure a well-trained and sufficient workforce by addressing the factors impacting recruitment and retention is important now and as the population ages and the need for home care and other services increases.

Conclusion

As families and communities come together to celebrate the holidays, we look forward to continued work with the Committee and Congress on a bipartisan basis to support our nation's family caregivers and ensure people have the services they need to live independently in their homes and communities where they want to be as they age.

Abilis is a Connecticut nonprofit supporting over 800 individuals with disabilities and their families. 45% of the adults we support have Autism. We launched our Supported Typing Program, (STeP) after incredible outcomes from a small sample in February 2019.

A STeP participant whose life has been transformed because of our program typed:

"I am free now of the frustration of not being able to tell you my thoughts and that has made a huge difference. People see me differently and I think differently. I now have hope for a freedom in my life that I have never had before. Please give me and others like me the chance to be the people that we really are."

We strive to build a community of typers and well-trained facilitators using best practices to ensure words being typed are the person's own authentic voice**.** For three individuals who were part of our 2019 sample, independent typing is now an emerging skill.

In March of 2020, with the onset of COVID, STeP moved to online coaching, training, social groups, and workshops. This unexpected shift allowed us to reach way beyond our catchment area. We have worked with typers and facilitators from 18 states, and from 5 countries. During the past 2 years, via Zoom, we have trained over 175 facilitators - which includes parents and staff members of agencies like Abilis from around the country. In some states there has been government funding for initial assessments, on-going coaching, and social group fees. Some states reimburse services provided by our program through self-determination.

Our clients and their families often describe the significant life changes that occur when someone learns to type to communicate. However, many school districts deny access to these typing methods even after parents and therapists have demonstrated successful communication when their autistic child is paired with a trained communication partner. Policy statements from some professional organizations, stifle educational opportunities for many. Their arguments rely on dated, limited, flawed research to deny services. Communicators feel unseen, disrespected and incredibly frustrated.

We ask that the IACC recognize that some forms of AAC such as FC, RPM and S2C are currently being utilized and are worthy of further scientific inquiry.

We suggest the following research opportunities

1. How can we better identify individuals who will benefit from FC, RPM and S2C?

2. How do individuals with a communication partner learn independence?

3. How can we measure the cognitive and social-emotional growth of typers and the impact on independent life skills?

Amy Montimurro, President & CEO, Abilis Inc
Susan Nisinzweig, Coordinator of STeP and parent
Deborah Hilibrand, Board Member and parent

December 8, 2025

Sen. Rick Scott
Chair
Special Committee On Aging
United States Senate
Washington, DC 20510

Sen. Kirsten Gillibrand
Ranking Member
Special Committee On Aging
United States Senate
Washington, DC 20510

Dear Chairman Scott, Ranking Member Gillibrand, and Members of the Committee:

ACLU
AMERICAN CIVIL LIBERTIES UNION

National Political Advocacy Department
915 15th Street, NW, 6th Floor
Washington, DC 20005-2112
aclu.org

Deirdre Schifeling
Chief Political & Advocacy Officer

Anthony D. Romero
Executive Director

Deborah N. Archer
President

On behalf of the American Civil Liberties Union (ACLU) and our more than four million members, we thank you for convening a U.S. Senate Special Committee on Aging hearing on Aging in Place: The Impact of Community During the Holidays. We write to elevate the urgent need to strengthen Home- and Community-Based Services (HCBS) for older adults and people with disabilities. HCBS is both a lifeline for Americans during the holidays (and all other days) and a civil rights imperative.

Following the enactment of the One Big Beautiful Bill Act, states are now grappling with significant reductions in federal Medicaid funding. The consequences of these cuts are already emerging, and they fall disproportionately on older adults and disabled people who rely on HCBS to remain in their homes and communities. While these cuts are now a reality, Congress still has both the opportunity and the legal responsibility to ensure that the civil rights guaranteed under federal law, including the right to live and receive services in the most integrated setting appropriate, are not eroded. Strengthening HCBS is the most effective way to achieve that goal.

HCBS is a Civil Rights Issue: the Mandate of *Olmstead*

More than twenty-five years ago, in *Olmstead v. L.C.*, the Supreme Court held that the unjustified institutionalization of people with disabilities constitutes unlawful discrimination under the Americans with Disabilities Act (ADA).[1] The Court explained the profound deprivation caused by unnecessary institutionalization:

> [C]onfinement in an institution severely diminishes the everyday life activities of individuals, including family relations, social contacts, work options, economic independence, educational advancement, and cultural enrichment.[2]

[1] 527 U.S. 581 (1999).
[2] *Id.* at 601.

The Court further held that states must provide services in the "most integrated setting appropriate" to an individual's needs[3] and that unjustified isolation and segregation is itself discrimination.

Congress enacted the ADA in response to generations of mistreatment and exclusion of people with disabilities. For decades, disabled people were segregated in unsanitary, unregulated, and often deadly institutions and subjected to forced sterilization in the name of eliminating so-called "undesirable traits." The ADA and *Olmstead* reaffirmed an essential truth: people with disabilities are full members of our society and are entitled to live, work, and participate in their communities just like everyone else. Fulfilling *Olmstead*'s mandate requires robust HCBS systems. Without stable access to community-based supports, older adults and disabled people face increased risk of institutionalization and segregation. The recent Medicaid cuts intensify this danger. Without congressional action, states scrambling to account for the cuts will end up violating federal law by pushing people into institutions. Congress can counteract this by reinvesting in the programs that make community living possible.

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HCBS Promotes Health and Autonomy for Individuals and Is Cost Effective

As former Acting Assistant Secretary for Aging and Administrator of the Administration for Community Living (ACL) Alison Barkoff testified, older adults and people with disabilities overwhelmingly want to live in their own homes and communities rather than in institutions.[4] Communal living, as opposed to institutional living, allows people to maintain relationships, health, and social participation.

HCBS also costs dramatically less than institutional care.[5] Yet, despite *Olmstead*'s community integration mandate, Medicaid law makes institutional care mandatory but HCBS optional. With the large cuts to Medicaid, states will be forced to only fund the programs that are required, leaving HCBS out. With our country's rapidly aging population, demand for HCBS will only grow.[6] Congress must act to meet this urgent need.

The Impact of the Recent Medicaid Cuts

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[3] *Id.* at 592 (quoting 28 C.F.R. § 35.130(d) (1998)).
[4] Testimony of Alison Barkoff before the Senate Special Committee on Aging (Dec. 3, 2025) (citing Joanne Binette, *Building for the Future: Creating Homes and Communities for Aging Well*, AARP (Dec. 10, 2024), https://www.aarp.org/pri/topics/livable-communities/housing/2024-home-community-preferences/).
[5] *Id.*
[6] Hannah Maniates, *Why did they do it that way? Home and community-based services*, National Association of Medicaid Directors (Apr. 16, 2024), https://medicaiddirectors.org/resource/why-did-they-do-it-that-way-home-and-community-based-services/.

Because institutional care is a mandatory Medicaid benefit and HCBS remains optional, cuts to federal Medicaid funding will inevitably fall first and most heavily on HCBS.[7]

We are seeing and will continue to see expanded waitlists for HCBS waivers, leaving hundreds of thousands unable to access services; shrinking provider networks as agencies struggle to operate with lower reimbursement rates; intensifying caregiver burden, with family members filling gaps without adequate support; and increased risk of institutionalization, especially for people with complex needs.

The stakes here have extraordinary human costs, as well as legal implications. When states force people into institutions, they run afoul of federal law, including *Olmstead*'s community integration mandate.

The ACL Reorganization Further Threatens Community Living

Alongside the Medicaid cuts, the Department of Health and Human Services implemented a drastic and deeply concerning reorganization and reductions in force that cost ACL almost half of its staff in 2025.[8] This decline in capacity undermines the Department of Health of Human Services' ability to oversee federal aging and disability programs, support states in implementing the *Olmstead* mandate, provide technical assistance and quality oversight for HCBS systems, and facilitate transitions from institutional settings to the community.

Additionally, this misguided dismantling of a critical agency means less support for Centers for Independent Living, State Councils on Developmental Disabilities, and Protection & Advocacy agencies, all of which protect the rights of people with disabilities across the states.

A diminished ACL leaves older adults and people without the federal partner they depend on during a period of heightened vulnerability.

Strengthening the Direct Care Workforce is Essential to Protecting Civil Rights

HCBS cannot function without a stable and skilled direct care workforce. Home care workers, personal care attendants, and other community-based workers—who are disproportionately women of color—perform essential labor that enables older adults and people with disabilities to live

[7] Jessica Schubel, Alison Barkoff, H. Stephen Kaye, Marc A. Cohen, & Jane Tavares, *History Repeats? Faced With Medicaid Cuts, States Reduced Support for Older Adults And Disabled People*, Health Affairs (Apr. 16, 2025), https://geigergibson.publichealth.gwu.edu/historyrepeats-faced-medicaid-cuts-states-reduced-support-older-adults-and-disabled-people.
[8] Barkoff testimony, *supra* note 5.

independently. Yet this workforce faces low and stagnant wages, limited benefits and inconsistent scheduling, few training or advancement opportunities, and turnover at crisis levels.[9]

Many home care workers already juggle their own conditions and precarious employment, making them particularly vulnerable to disruptions in Medicaid policy. These workers have also long been excluded from workplace protections that the vast majority of professions enjoy, and not by accident. Racist polices dating back to the New Deal era treated home care workers as "companions" to seniors and people with disabilities.[10] While that exemption under the Fair Labor Standards Act was removed in 2013, the Trump administration has proposed reopening that exemption to prevent care workers from receiving minimum wage and other workplace protections.[11] A meaningful federal investment in the direct care workforce is critical and long overdue.

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Without a strong workforce, older adults and people with disabilities will face longer waitlists, fewer service hours, and a significantly heightened risk of institutionalization.

We thank the Committee for convening this important hearing and for considering our views. We look forward to working with you, and other Members of Congress, to ensure that the health, safety, and civil rights of older adults and disabled people are protected. If you need additional information, please don't hesitate to contact Vania Leveille at vleveille@aclu.org.

Sincerely,

Mike Zamore
National Director, Policy and Government Affairs

Vania Leveille
Senior Legislative Counsel

Jacob I. Abudaram
Jacob Abudaram
Skadden Fellow, ACLU Disability Rights Program

[9] PHI, *Direct Care Workers in the United States: Key Facts 2024*, https://www.phinational.org/national-resource-center/resource/direct-care-workers-in-the-united-states-key-facts-2024/
[10] April Verrett, *Home Care Workers Are Now Called Essential. But the History of the Profession Shows That the U.S. Has Never Treated Them as Such*, Time (Aug. 24, 2020), https://time.com/5882416/home-care-workers-racism/.
[11] Application of the Fair Labor Standards Act to Domestic Service, Fed. Reg. 12316 (proposed July 2, 2025) (to be codified at 29 C.F.R. pt. 552).

Doni Martin, works for a service provider in a role other than direct support
Brandon's Story
The Doni Martin Center for Developmental Services
Corning, Arkansas

Brandon graduated from his hometown high school. He and his guardian wanted him to learn skills to eventually live on his own, possibly with supports. The first thing the agency did was help him apply for HCBS funding. Then he chose to live in our 10 bed group home and as part of his plan learn to shop, manage money, do laundry, and other independent living skills.

He worked part-time with supported employment for a few years. Due to a medical problem he was forced to quit. Brandon has a mild intellectual disability and cerebral palsy . After a few years of living in the group home he was able to move to an apartment complex with part time support staff provided through HCBS funding.

He attends adult day treatment a few days a week, rides an adult tricycle for regular exercise and visits family and friends who live nearby. He is proud of his accomplishments and the fact that he moved into his apartment 10 years ago. His success is because of availability of HCBS funding.

Cheryl Sasaki, works for a service provider in a role other than direct support
Vista Care Colorado, LLC
Aurora, Colorado

I worked with individuals to help them find integrated employment. During the process, we visit different employers, explore various positions that align with the job seekers strengths and employer needs. I support building a resume, practicing interviewing, during interviews and once hired, the on boarding and training. I offer long term job coaching support to ensure the individual AND the employer's needs are being met. The employers love the support. The individual loves the support and independence they gain from retaining a meaningful job just like you and I.

Support is vital for long term success and I believe my dream job is helping them find (and keep) their dream job. Supports are needed and vital! If these services were not available, the world will miss out on meeting all the beautiful souls with disabilities working to make a difference. WE MAKE A DIFFERENCE FOR THEM!

Marty Kemmer-Contreras, caregiver of a family member that receives I/DD services
Cheyenne Village
Colorado Springs, Colorado

After high school and completing her transition program, Annie faced isolation from our community. After my husband passed, I was working full-time, and as a young woman with special needs and I/DD, she had very little connection to the world outside our home during the day. It was a lonely and uncertain time, and I often worried about her future.

Then we found Cheyenne Village, a nonprofit in Colorado Springs, and Annie began attending their day program. At first, it was a slow process, but the dedicated direct service staff guided her with patience, encouragement, and care. They helped her gain confidence, make friends, and feel like she truly belonged.

About a year later, everything had changed. Annie eagerly talked to her friends on the phone each evening, participated in community events, and had a life of her own. She is now 30 years old, and while she has made remarkable strides, I live with the constant fear of what will happen to her when I am gone. As her aging caregiver, the thought of her facing the world without the support she deserves is always in the back of my mind. We are still on the waitlist for the DD waiver, and I want her to have the opportunity to continue growing, living independently, and making a true difference in our community. Annie deserves a life full of connection, purpose, and joy—and the peace of knowing she will be cared for and supported, even when I am no longer here.

John Townsley, a caregiver for a family member receives I/DD services
Lewes, Delaware

We live in Sussex County, DE and there is a paucity of group homes or living opportunities for older individuals with disabilities. As we approached our senior years we found it very difficult to find a group home for our son. Home based services are extremely limited. Job opportunities for I/DD individuals are virtually non existent. The need for programs and services (ie job support staff) are need to help these individuals become working members in the community as well as living members in the community.

Cheryl Plank, works for a service provider in a role other than direct support
Charlie's Story
Imagine the Possibilities
Maquoketa, Iowa

Charlie is a long time Iowa resident and has spent many of those years as an Imagine member. It is no doubt that Charlie has become and remained an impactful member of his community, as he is named the honorary fire-chief of the Winterset Fire Department. Charlie's interest began with a love of firetrucks, which he collects and displays around his bedroom. From then on, Charlie has made connections with the department. Charlie explains some of his favorite moments being involved with the fire department: "I like to listen for the fire whistle and watch them [the fire trucks] go in a hurry!" Charlie's eyes lit up as he explained the joy he receives from the local heroes, telling those in the room that they have shown up for him on multiple special occasions, including his most recent birthday. Aside from local activities, Charlie is a life-long Iowa Hawkeye's fan. When asked about his favorite team, Charlie explained that it was obviously football. There was no other choice! The connections Charlie has with his community are a reminder of the impact of Community-Based services. We thank Charlie for sharing his story with us.



Cheryl Plank, works for a service provider in a role other than direct support
Phil's Story
Imagine the Possibilities
Maquoketa, Iowa

Phil is a life-long Iowa resident and has spent many of his years with Imagine. During his time, he has made a significant impact on his community, deepened his love of fishing, and formed lasting relationships with members of his care team. When asked about his current living arrangements, Phil explained, "I'm totally happy with everything I have now...It's my home." He expressed that the level of care and comfortability provided by his team has made a significant impact in his life, and he is appreciative of everyone in his circle. "I'm really happy with my team. I like the way things are set up now." Of course, it wouldn't be a conversation with Phil if a couple of jokes weren't cracked. "We [Phil and his team] sneak off and let everyone know that we are!" The ruminating laughter of Phil's team and other Imagine members was proof of the direct impact made on the lives of individuals at Imagine the Possibilities. We thank Phil for his time and for the laughter we shared.



Cheryl Plank, works for a service provider in a role other than direct support
Jeremy's Story
Imagine the Possibilities
Maquoketa, Iowa

Jeremy is an Iowa resident and a member of Imagine the Possibilities. Through Imagine, Jeremy currently attends the Day Habilitation Program. While speaking with Jeremy, we gained insight into his day-to-day life, his hobbies, and his current living arrangements. He explained that he currently lives with three other individuals, all of which have grown into friendships. Jeremy stated that he prefers living with roommates, as it helps him to "not feel alone."

Since Jeremy's home is located right outside Jefferson Town Square, he often engages in community activities, including shopping down the strip, enjoying local festivals, and simply taking walks to get exercise. During Day Hab services, Jeremy and his peers often visit shopping centers, participate in Day Hab dances, and volunteer at the local animal shelter. When Jeremy was asked his opinion on the services he receives, he stated, "I really like it...I have a lot of fun and have made a lot of friends." Thank you, Jeremy, for taking the time to chat with us.



Cheryl Plank, works for a service provider in a role other than direct support
Chester's Story
Imagine the Possibilities
Maquoketa, Iowa

Chester is a long-time Iowa resident and an Imagine the Possibilities member. Over the years, Chester has connected with his community, made lasting friendships, and adopted new skills through Imagine services. Chester gave insight into one of the service programs he participates in- Day Habilitation. He explained that, during the Day Hab program, many activities take place. Some of his favorites include learning and playing new games, mingling with his peers, and tackling new life skills he takes an interest in. Chester enjoys the times he can connect with his community and explained that he often finds joy in being "out and about." We are grateful to Chester for his time and willingness to share his passions with us.



Cheryl Plank, works for a service provider in a role other than direct support
Margaret's Story
Imagine the Possibilities
Maquoketa, Iowa

Margaret has spent over a decade with Imagine the Possibilities; having watched mergers, leadership changes, and regional restructuring. She's been here with us through it all, yet her passions have remained constant. Margaret explained to us that Imagine has helped her cultivate new and thriving hobbies over the years – ones that bring immense joy and help grow her creativity. Jewelry making is one of her biggest passions, as the relaxing past time has inspired sparkly creations for herself, friends, and family. Margaret especially adores creating with her favorite color, purple, explaining how beautiful she finds it in everything.

When asked about some of her favorite adventures over the years, Margaret smiled ear to ear as she described her experience at Harry Potter World in Orlando, Florida. Thanks to Able Trek and some amazing care staff, Margaret got the chance of fun, adventure, and a whole lot of magic. But most importantly, Margaret reminded us of the importance of being kind. Care staff explained that her big smile and warm hugs instantly brighten their days, and the pranks she pulls with her friends spark laughter and a fun atmosphere. We thank Margaret for sharing her passions with us.



Cheryl Plank, works for a service provider in a role other than direct support
Brian's Story
Imagine the Possibilities
Maquoketa, Iowa

Brian is a long-time Iowa resident and Imagine the Possibilities member. During our chat with Brian, we learned about his hobbies, his incredible worth ethic, the things he's most passionate about, and the past-times that keep him smiling. Brian attends Day Habilitation services, where his passion for work thrives. During his time at Day-Hab, Brian is able to sharpen his skills, gain real world knowledge, and learn how to apply it to his daily life. Brian explained that, with the skills he's gained through Day-Hab, he has grown to love chopping wood with his dad – an activity that has strengthened their relationship. He explained how important family is to him and how excited he is to be attending his sister's wedding at the end of the month. Brian was eager to tell us about the things he enjoys in life, including getting exercise at Yogi Bear Park, eating some fresh Iowa sweet corn, and attending Tim McGraw concerts! We thank Brian for taking the time to speak with us.



Cheryl Plank, works for a service provider in a role other than direct support
Mary's Story
Imagine the Possibilities
Maquoketa, Iowa

Mary is an Iowa resident and Imagine member, having been with Imagine for many years. Mary's enthusiastic energy lights up any room she enters, and her smile helps tell her story of joy. When speaking with Mary, we learned how much she loves living in an Imagine residence, explaining that she can form connections and gain independence like never before. She also remarked on the experiences she has had. Mary shared how grateful she was to have attended the local fair and even a Skillet concert! Our chat with Mary served as a reminder of the incredible impact of community, teamwork, and a dedicated care team. We thank Mary for her time and wish her the best of luck at Imagine.



Cheryl Plank, works for a service provider in a role other than direct support
Jesse's Story
Imagine the Possibilities
Maquoketa, Iowa

Jesse is an Iowa resident and Imagine the Possibilities member of over 30 years. Our conversation with Jesse was extra special, as a surprise visit from Dad turned our chat into a heartfelt message of the importance of strong family bonds. Before our surprise from his father, Jesse described to us his interests – including landscaping and a natural gift for memorizing numerical sequences. He shared how excited he was to see upcoming shows in August, including The Little Mermaid and the horse show.

Just as Jesse was explaining how grateful he is for his father, Tom entered the room for a surprise visit! Emotions were high when Jesse's eyes lit up in excitement. The joy Jesse had seeing his father was a reminder of just how important it is to have a strong support system, especially one that will show up when you need it most. After the excitement of Tom's entrance settled down, we got to chat with him briefly. Tom explained how happy he was with Jesse's care team and routine at Imagine, making it a point to mention Jesse's 31 years as an Imagine member. When asked about the effects of the most recent merger, Tom explained that he felt none, reassuring the decision as one that drove our mission and organization forward. We thank both Jesse and his father Tom for their time. Their conversations reminded us that relationships with loved ones mean everything, showing up for those you care about matters, and decisions to move our mission forward are always worthwhile.



Allyson Kelley, works for a service provider in a role other than direct support
Communitas
Wakefield, Massachusetts

I started off my career at Communitas as a direct care support staff at the day program and when Covid hit, I went into the residential program as a direct care staff and then I became an assistant manager in the group home I became a direct care staff. And a few years later I became a director at the group home. The impact IDD services has affected my life is something that is hard to describe. All my life I have had dreams of making a difference in people's lives and through this job I feel I have an impact on the ladies i support every day. Watching them achieve goals and live the lives they deserve is why I decided to do the job I do.

I feel direct care support professionals make a difference in the individuals we support because without them the individuals would not be able to have the opportunities they do and would not be able to receive the care direct care professionals provide to them every day. I feel direct care professionals build relationships that will last a lifetime for both the individuals we support and for the direct care professionals themselves. For myself I feel i build relationships with my individuals and staff every day and while I am trying to make a difference in their lives, they are making a difference in my life.

In our community if services for IDD were terminated and limited it would play a huge impact on the people we support because they would be lost and would not have the opportunities they do now. I also feel it would play a big impact on their families because it would put more responsibility on them without the services for their loved ones.

I feel my work as a direct care professional and now as a manager has played a huge impact on the lives of the people I support, through supporting them through their challenges and being there for them through their successes.

Ashley Evans, works for a service provider in a role other than direct support
Rochester, Minnesota

The individuals I've seen in our HCBS programs have grown and become part of a community that many never thought they would be able to. Our art program has seen individuals go from depression and sadness - creating art in dark and moody colors - to feeling welcomed and safe with vibrant hues. I've witnessed an individual blossom being able to communicate with staff better thanks to biweekly ASL classes. We can meet him where he is, and it means the world to have him telling stories to us and the teachers of the class.

I've heard countless stories of families being told their child would be a burden and should be given to the state or put in an institution without so much as a second thought. Too many individuals we work with have horror stories from their schools not putting a stop to bullying, not allowing for proper support or resources, and a wealth of misunderstanding and misinformation. When people make their way into services, we are able to show them there is a community of kind people here to support them - not because they are disabled, but because they are people.

We've had many individuals who've never met people with similar disabilities to them until they got to the program, and there is a wealth of inherent understanding and safety then. Access to these services allow us to support people's journey through education, employment, and life. We also work to undo years of damage and trauma and remind them that they matter.

If these services were limited, many individuals would have a huge reduction to their freedom, face increased depression and anxiety, and isolation. Those receiving in home support or respite service would be affected as well with quality of care lowering as family and caregivers would need to find other ways to support the family, burnout, anxiety, and depression would skyrocket among families/caregivers, and other resources in the community would be taxed instead.

Most importantly, their ability to thrive would quickly diminish as there is still an unbelievable amount of work to be done to create supportive communities that don't need the support of HCBS providers. Losing one's sense of belonging is devastating, and we help individuals find that within themselves. If that gets taken away, we hope they would continue with the lessons and skills learned, but it is just as likely to have terrible consequences. HCBS not only supports but creates community.

Heidi Smith, works for a service provider in a role other than direct support
STEP, INC.
Fairmont, Minnesota

I am so proud of our organization, STEP, Inc. In our small towns of Blue Earth and Fairmont, Minnesota, we have made the decision to provide the best services to the persons with disabilities in our community. This means we invested in a large space for Day Services, we traing our Job Coaches to support our individuals in a person-center manner, and even started IHS services (In Home Services) to help those that need more independence. Terminating services means our individuals will no longer be advocated for and with by our DSP's. Our DSP's make ALL the difference. They understand the mission and why we do this incredibly important work.

STEP, Inc. even has a "Why" statement: "We are an organization that provides innovative services through compassionate and dedicated individuals that go above and beyond to help everyone find their purpose, passion, to have their best journey ever and empower them to make their dreams come true!" Take away services and who is going to take this mission and make in happen in communities?

Chrystal Wheat, a direct support professional
Able Services
Glen Rock, Pennsylvania

Community-based services are one of the reason the adults with I/DD in our program stay active and connected. As a DSP, I see how these supports keep people out of nursing homes and give them opportunities they would never have otherwise.

One of the individuals I support, “John,” is in his 60s. This year he got to climb through a mock smoke-filled fire safety house at our local fair. He was thrilled. He loves fire trucks. He completed the whole course with confidence. I truly believe that if he were in a nursing home, he wouldn’t have the mobility, support, or opportunity to do something like that or build relationships with our local firefighters.

DSPs make moments like this possible. We keep people mobile, engaged, and included in their communities. Without HCBS and DSP support, individuals like John would lose independence, connection, and quality of life.

Community-based services don’t just help people live — they help them thrive.

Keisha Turner, a person who receives I/DD services
Hope House Foundation
Norfolk, Virginia

I am 44 years old. I'm diagnosed with an intellectual disability as well as a congenital hip deformity. I live in the Tidewater Park area of Norfolk, VA. I have been living on my own for over 20 years. I am independent for the most part, however I rely on direct support professionals to help me with medication reminders, daily hygiene, keeping my apartment clean, and planning a healthy menu for the week.

Before I lived on my own I was not able to make my own choices. Having my own apartment and community based services have helped me learn skills to be successful at volunteering and work. If my services were terminated I would be unable to be independent and live the life I choose.

Stories Submitted by the Autistic Self Advocacy Network

Their Future Depends on You!

Written by Kathleen O'Connor on December 7, 2025

Home and Community Based Services (HCBS) has helped our grandson who has disabilities (Intellectual disability – mild & autism) stay in our community. Without HCBS, he would not have the services and supports he needs to stay out of an institution. With direction and HCBS support, he is able to function. We are very proud that he was one of 13 students selected as Freshmen for the UC Davis, Redwood SEED (Supported Education to Elevate Diversity) program. A huge component of the program is learning to live independently and to gain employment with a competitive wage. He lives in a dorm and has the support of mentors who help teach him independent living skills. He currently has a meal plan but the curriculum provides for learning to prepare simple meals by the junior year. HCBS funding through Medicaid is essential to keep our grandson out of an institution. Unless he is allowed to have these necessary supports, we fear that will be his life's outcome. Redwood SEED Scholars has the tools, with the assistance of HCBS to help him become independent. Please do not jeopardize the lives of those least able to defend themselves by eliminating HCBS from Medicaid. Their future depends on your wisdom and vigilance in defending the rights of the disabled. Thank you,. Kathleen R. O'Connor

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Independence Now (PG County CIL) & HCBS means I can live independently!

Written by Noor Pervez on December 1, 2025

Hi! My name is Noor, and I live in Prince George's County in Maryland. I moved here right after college. I am an autistic adult with Hypermobile Ehler Danlos Syndrome (hEDS), POTS, IIH and cervical instability. For me, that means I use a power chair for my own safety, because I pass out very often, and am high risk for spinal cord injuries. Independence Now has been a key part of connecting me with disability resources and supports in my area. They helped me understand the laws around disability and housing. When my old apartment complex would not answer me after months of trying to ask if I could pay for a safer ramp at our back entryway (the one we had was not ADA compliant, and I nearly fell out of my chair a few times) they helped me connect with people I could report them breaking the rules to. Between them and some of the resources they directed me to, the ramp did get built, and other safety modifications I needed - like a grab bar in the tub - also happened. As I get older, my chronic illnesses are going to make me weaker. I know from watching my mother that I will continue to struggle with joints popping out of place more often, and will likely need an hip replacement once I am in my forties. Independence Now has been critical in me planning for my future. They explained about a program Maryland has that will allow me to get coverage for PCAs (home health care, also known as home and community based services) with secondary coverage from Medicaid *only* for these services,

while still allowing me to work, as long as my income is below a certain threshold. PCAs can do things like helping me with bathing, meal prep, picking up and managing medications, and driving to doctor's appointments. This will allow me to continue working significantly longer than I thought possible when I first got diagnosed. Working means that I can keep doing what I love. These services will let me participate in my community as my disability progresses. I can keep going to religious services, tutoring English at my local library, and volunteering with my local service dog training nonprofit. It would be impossible for me to do this if I was struggling to feed and medicate myself - something that's already difficult when I'm young and sick, and that's going to be a lot harder when I'm older and sicker. The CIL and HCBS are critical lifelines for me as a disabled person. They mean that I can continue being a part of the world. They mean I can eat, exit my home, go to work and have fun with friends and family. When a close friend in my local knitting community circle found out she had a terminal, aggressive form of brain cancer three years ago in the emergency room, the CIL helped me with showing her how to apply for Medicaid (she was previously uninsured). They helped us apply for HCBS, and showed us how to ask if they could expedite the application given the circumstances. She was granted in home help, and it made it possible for her to have a good life in the remaining time she had left, even as her physical health rapidly got worse. She was able to get in home physical therapy to learn how to use a wheelchair safely, and how to bathe safely as a new fall risk. Someone was able to help make sure she had meal prep for the week, so that she just had to microwave something to heat it up. The CIL helped us find a contractor that could build a ramp on her house quickly, and helped us connect to resources for the blind so that she could still have media, like books, as her vision went out in her last year. She had the ability - the dignity - to see her friends, to knit with us, to see the cherry blossoms, for as long as possible, for her last three years. I am eternally grateful for the CIL and HCBS for making my friend's life livable. She had no family - just a few friends, and all of us work full time. She was able to have a good life in the time she had left, despite the circumstances. Nobody should have to spend the last years they have on earth fighting for their basic needs to be met. Because of these resources - she didn't. Please continue funding the CILs and HCBS.

My son

Written by Ann Shieder on December 4, 2025

I/we need HCBS services now more than ever. I am writing on behalf of my 27-year-old son, who has Autism. Thanks to some HCBS services—services I had to fight for over many years, and which still remain inadequate—my son was able to graduate from high school and earn a two-year college degree. The support he received before age 21 was substantial and meaningful. After turning 21, however, those services dropped off to almost nothing. Mostly due to the Department of Rehabilitative Services having too few workers and being underfunded. As a parent, I have had to step in to fill every gap: advocating, job coaching, and doing everything

possible to help him find and maintain employment, which remains minimal at best. The greatest need for HCBS is at the adult level, when individuals like my son are expected to navigate employment, finances, housing, and daily living with far less support or no support. Adults with disabilities need consistent help with budgeting (I still manage my son's finances), writing resumes, preparing for job interviews, and securing stable housing. Without these supports, my son will never be able to live independently or fully contribute to his community. As my husband and I age, I become more concerned about what he will do without us. We have spent years helping him develop skills and confidence, and he is still better off than many of his peers whose families may not have the time, resources, or knowledge to advocate as intensely as we have. My hope is that the government will prioritize helping adults with disabilities access meaningful employment and will invest in training employers to understand their strengths rather than underestimate them. These individuals are often highly intelligent, capable, and motivated—they simply learn differently and may require longer training periods. My son's employer once told him that he is "consistent and reliable." Isn't that exactly what every employer wants in at least half their workforce? Overachievers are easy to find. Consistent, hardworking individuals are not. Please take meaningful action to strengthen and expand HCBS services for adults with disabilities. Their futures depend on it.

Why I Can Live At Home and How I Got my College Degree

Written by Dorothy Reinhardt on December 2, 2025

I have Cerebral Palsy which means my muscles don't work the way I want them to. I depend on aides funded by HCBS to help me with my day. My aides help me with eating, dressing, and personal hygiene. Without them I could not live at home. But they also enable me to participate in the community. Because of HCBS I was able to attend my local community college and later enroll in a state university and earn a Bachelor's degree. Because of Medicaid funded HCBS , rather than living in an institution, I can look forward to volunteering with children, who like me, rely on augmentative and alternative communication (AAC).

Brian Long's Story About Why He Needs Essential

Written by Brian Long on November 24, 2025

My name is Brian Long and I am 50 years old. I live in Selinsgrove, PA. I live with two roommates who help support me. They are called Life Sharers. I can't live on my own, but I can be alone for extended periods of time if I have someone checking in on me. I really like how my life is now. I have my own bathroom and bedroom and share a kitchen, living room, laundry, and dining room. I've lived with people before who didn't care for me and I was unhealthy and had bad hygiene. My roommates work for Shared Support, but they are like extended family

to me. With Shared Support, I have a DSP, who helped me find a seasonal job, and he is my job coach. When I'm not working, I attend classes at the Arc and I have learned how to manage my money, how to cook, and I am now able to budget my money and make more choices about what I want in my life. I have lost nearly 200 pounds over the last seven years and my health has improved significantly. My DSP and my Behavioral Specialist helped me create a plan to quit smoking. I ride an exercise bike for 12 miles three times a week to keep my heart healthy.
 I have experienced a lot of loss in my life and so I don't have family members who can help me. Having paid supports is essential for me. Because of the help I get from my provider I can work, exercise, go out to eat, go to dirt track races, go fishing, participate in a bowling league, and volunteer at at a coffee house. I have made some amazing friends because I am not stuck in my house or in an institution. I do not want to be forced to live in any places other than when I want to live. I know I need help with some things and I need all that I have right now. When I didn't get SNAP, it made things really hard, but my DSP helped me go bargain shopping to stock my pantry and I was able to get through that. People who don't have help are really having a hard time. I would appreciate it if you make sure people like me and my friends get the essential help we need. If we don't get this help, we can't contribute, and regardless of what people say about us, we all want to. We want jobs, we want to volunteer, we want to have friends and go to community events. We want to be as independent as we can. So please, allow us the dignity of doing all that we can for ourselves by giving us the help we need to do that. It is what is right. We believe in America. Please ensure America believes in us.
 God Bless You, Brian K. Long

Disabled Lives Matter

Written by Julia Simko on November 27, 2025

My HCBS waiver helps me with transportation. Without it, I wouldn't be able to go anywhere including, but not limited to, college classes, church services, and the polls to be a board worker at election time. You thought the quarantine was bad? Try living your whole life like in one! I'd starve to death, live my life unemployed, and possibly be homeless. I'm in college and do volunteer work when I can, so I can get a job that's not entry-level someday, and I'm hoping that by being a student (and a full-time one at that) I'm not negatively impacted by the work requirements. The Center for Independent Living (CIL) in the county I live in in conjunction with the Division of Vocational Rehabilitation (DVR) offers a class that helps people with disabilities prepare for the written test for getting a Learner's Permit for driving. I hope to go through that program someday myself. It also offers a Mental Health First Aid certification course that I also want to go through. It's helped so many people in my county and one other one with a ton of different things.

Hope for the Future

Written by George Doersch on December 7, 2025

My grandson has an intellectual disability (mild) and autism. His mother is deceased. His father is homeless but has a job. He has no one but his grandparents and one aunt to rely on. I will be 80 in March 2026. I worry about what will happen to my grandson if he cannot obtain the necessary independent living skills. Only one college in California, University California, Davis, offers a four-year program, the Redwood SEED (Supported Education to Elevate Diversity) program for young adults who are intellectually disabled such as my grandson. He is so blessed to be able to live in a dorm where he practices independent living skills. When he is a junior, he will be placed in an apartment on campus and will learn to cook! These offerings are due to the Home and Community Based Services (HCBS) currently available to him through Medicaid. He just finished his first quarter of college in the Redwood SEED program and already I can see what a difference in his abilities to live independently. Please, please, do not delete this funding. It is essential to provide the services and supports he needs to become truly independent. Having the HCBS in Medicaid gives me hope that even after I die, my grandson will have gained the skills necessary to live independently in his community. Thank you for allowing me the opportunity to comment. George R. Doersch

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Please continue to fund HCBS. My autistic daughter really benefits, and so does our family!

Written by Sadie Owocki on December 1, 2025

My seven year old daughter is autistic and receives supports coordination services, which is a form of HCBS. The supports coordination agency makes an Individual Support Plan (ISP) in consultation with her and me, and they help connect me to services to implement that plan. I think of it as a practical, everyday type of IEP (Individual Education Plan). She has an IEP to help her access a Free Appropriate Public Education at her school; the ISP is for everything else, because while school is important, living as part of a community is so much more! Working with the supports coordination agency is an important part of raising her to be a strong self-advocate who can continue to grow and live in her community into adulthood. It is also an important form of assistance for me as a parent. I am an autistic adult who has never been eligible for such services as I was diagnosed too late (which is a whole other story really). Through accessing services for my daughter, who was diagnosed early, I get to unlearn and challenge lots of assumptions that I have as a parent. For example, although my daughter is not diagnosed with an intellectual disability, I really benefit from the supports coordinators' expertise in working with individuals with a range of disabilities, including intellectual disabilities, and centering those individuals' goals for their lives. I also benefit from my daughter being eligible for Medicaid in our state due to her special needs. It allows me to access more therapies for her and to better support her than if I had to support her only through private insurance, which can be expensive

and confusing as a single working parent. In short, please continue to fund HCBS and Medicaid access for people with disabilities. It benefits everyone in the long run when people with disabilities can be part of our communities by design. Thank you.

ShyLynn Flowers

Written by ShyLynn Flowers on November 24, 2025

I am 29 years old and I live with other people like me. I have a job coach, go out into the community, and am proudly in a relationship, All of this is aided by the services I receive without which I am not sure where I would be. I am friendly and kind and have been awarded at my job for being a hard worker. All I need is a little support to thrive.

Institutionalize her.. It's your only choice

Written by Marian DeSimone on November 29, 2025

"Institutionalize her, it's your only choice, she'll never be a functioning member of society". These are the exact words spoken to me by the head of pediatric neurology at Scottish Rite Hospital in Atlanta in 1995. Fast forward to 2025, Bernardsville NJ. Meet Daisy, my daughter. She holds jobs at the YMCA (15 years) and CVS (11 years). She lives in local low-income housing, independently but with support funded by the state of NJ DDD budget. She is a member of 2 local gyms, participates in Special Olympics, works the election polls, and volunteers at Mane Stream adaptive riding and much more. What makes this journey remarkable is that a human who was being directed to an institutionalized life was able to achieve so much, simply by living in the community. Over the years teachers, coaches, employers, friends, neighbors, classmates and co-workers had a chance to interact, support and influence Daisy in a way that helped her lead a fulfilling life and at the same time enlightened her community to what is possible. That is the beauty of Community living. It makes the world a better place for everyone. And if that wasn't enough, it does it with a documented lower cost for all parties involved. Thank you for letting us share our story.

Living 3,000 Miles Away at College

Written by Patrick Foraker on December 7, 2025

My name is Patrick Foraker. I am 26 years old and have Down Syndrome. I live in Davis, California but I went to an inclusive college program at George Mason University in Fairfax, Virginia for four years. I was able to live with my friends in the program and a support person. We had so much fun! I went grocery shopping at Giant. I made my own food. I had movie nights

with my friends. It was the best. People with Down Syndrome should get to go to college and live with friends, just like everybody else. HCBS makes that happen. Thank you.

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58 communication

Written by John Yocum on November 24, 2025

I am a 58 year old man with an intellectual disability. I can verbally communicate, however I need assistance comprehending. I would like to find a job so I can earn myself some money to do outings I enjoy, Without the staff and my community living arrangement my quality of life could go down quite a bit.

David Hasuga

Written by David Hasuga on November 24, 2025

I need help getting out in the community, that is why I need support staff. Rachel my house mom took me in to give me a great home and boy has my life improved. Without her and her support I would be in an institution. My support staff takes me to the library shopping, out to eat, and to social events. My house mom(assisted by Medicaid) provides me a safe and friendly home environment and provides food, medication laundry and other activities of daily living.

To find a forever family

Written by Neil Kalcich on November 24, 2025

I live in a group home provided Medicaid. I do my best to work in the community with support. I enjoy being social and attending programming, All of this is made possible by the services provided by Medicaid.

Liv's

Written by Patti Adams on December 7, 2025

When we adopted Olivia at age 17 months we only knew two things about her - she had Down syndrome and loved Winnie the Pooh! Our dream for her has always been that she live a life of inclusion and opportunities - the same as her two older siblings that do not have disabilities. Thanks to HCBS, that dream has come true. Thanks to the Independent Living Skills instruction at Redwood SEED Program at UC Davis (funded by MediCaid) Liv learned the skills needed to take care of herself and manage an apartment. Now at age 28, she lives a life of her choosing - in

an apartment with roommates, working 18 hours per week. She continues to receive support through Medicaid which makes her supported life possible. With Medicaid resources, I know she will be able to live her life long after I, as her mother, am gone. Should Medicaid services be removed, her only alternative will be to move home and live with her family long term. Nobody wants that! I urge you to continue to support and fully fund Medicaid for our most vulnerable populations. Thank you.

Why Gretchen's independent living matters

Written by Grace Wahle on December 7, 2025

Dear Senators and Committee Staff, My name is Grace, and I am writing as the proud sister of Gretchen, who is currently a student in the Redwood SEED Scholars Program at UC Davis. I want to share what independent living means for her—not in theory, but in our family's real, everyday life—and why Home and Community-Based Services (HCBS) are absolutely essential to making this possible. Growing up, Gretchen was always full of joy, curiosity, and determination. But as she approached adulthood, our family kept encountering a heartbreaking truth: opportunities for people with intellectual disabilities are incredibly limited. Most inclusive college programs in the United States are only two years long, and 90% provide no inclusive living options at all. For students like my sister, that means aging out of high school and immediately being channeled into programs that keep them dependent, isolated, or stuck at home—no matter their potential or dreams. The Redwood SEED Scholars Program at UC Davis changed that for Gretchen. For the first time, she is not just attending classes alongside her peers—she is living alongside them, too. She has a dorm, roommates, responsibilities, and independence. She is learning to cook, clean, manage her schedule, make friends, and navigate a campus community. She is building the life every young adult deserves the chance to experience. This independence is possible because the program offers an inclusive living option, something incredibly rare nationwide. And because of that, the program qualifies for Medicaid HCBS services, funded through California's Regional Centers. These services support both the independent living portion of the program and the mentors who guide the students day-to-day. Without HCBS, Gretchen simply wouldn't be able to attend the program. She wouldn't have the support she needs to live safely on campus. She wouldn't be learning the skills that will allow her to live independently in adulthood. HCBS isn't just a funding mechanism. It's the bridge between dependence and self-determination. As her sister, I have seen Gretchen grow in ways that would have been impossible without this opportunity. She calls me to tell me about her friends. She grocery shops on her own. She solves problems without needing to rely on our parents. She is proud of herself—and she should be. This is what true inclusion looks like. The Autistic Self-Advocacy Network shared that the Senate Special Committee on Aging is gathering stories to help shape upcoming policy decisions about disability services. I want you to know that programs like Redwood SEED—and the HCBS services that sustain them—are not luxuries.

They are life-changing, future-opening necessities. They allow people like Gretchen to live, learn, and belong in their communities, just like any other young adult. Most U.S. Senators have never heard of inclusive college programs for students with intellectual disabilities. I hope Gretchen's story helps change that. The decisions you make directly determine whether opportunities like hers will grow—or disappear entirely. Thank you for taking the time to hear about my sister. I hope you will continue to protect and expand HCBS services, and ensure that inclusive college programs with independent living options remain accessible to students who deserve the chance to thrive. Sincerely, Grace

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In my Words

Written by Mark Reeves on November 24, 2025

I am 57 years old, living with Down Syndrome and Autism. I work and own my own home with out my staff/support I would not be able too live alone, cook meals do household chores, and take my medicine. I have staff transport me to and from work that assists me when needed. I could not imagine having to deal with any other arrangements, without support I would not be able to thrive. I use assistive technology to communicate with assistance so my voice, opinions and concerns can be heard and expressed. I would not be heard at all without staff assisting me. I enjoy living in my own home and my job. It is crucial that I have extra supports to live a happy healthy life.

My name is Tiffany

Written by Tiffany Richard on November 28, 2025

My name is Tiffany and I'm autistic and have ADHD. If it wasn't for school accommodations, I would have a difficult time going through college. Being able to receive extended time and a reduced distraction testing environment helps me be successful.

It's very important

Written by Anna Leah Swafford on November 28, 2025

It's very important for me to use these services so that I can go out in my community

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I Did It!

Written by Natalia Sweet on December 7, 2025

My name is Natalia and I would like to let you know that I have an intellectual disability and an Expressive and receptive language Disorder and a Learning disability. It is hard for me to understand things like for example when I read a book it is hard for me to understand. It's easier for me to learn when the teacher talks a little bit slower. I was accepted into the Redwood SEED Program at UCDavis and I have loved every single minute of my time here. It helps me to be independent and I have made new friends who are like me and I also get to walk around campus and see myself as a regular college student on campus. I can find my way around campus independently. I live with friends in a dorm. And I learn new things every day. Next quarter I am excited to be in a regular UC Davis class that has 500 students and I will be working on campus helping at the Equestrian Center. I am so excited!! Without the Redwood SEED program, I would be at home alone and not doing much. I am thankful for the opportunity to be on campus, away from home, on my own, like my brothers. I also learned a lot last summer before I got accepted into the program when my mentor at DOR helped me find a job working with people with Alzheimers and dementia. And I would feed them lunch every Friday. And I would bike from the center back home by myself. Sometimes I would go and it would make me think I wasn't alone when I would talk to them. I have memory issues too. My mentor told me many times that I was helping them and did a very good job with them, even if they were sometimes crabby. Thank you for giving me this opportunity to share my story. I am very, very grateful that I have these options. And I'm grateful that I did it with my mom and dad's help and your help too!!!

When my daughter was

Written by Chris Chun on December 7, 2025

When my daughter was in utero, she almost died. It was a medical miracle that she was born at all! Because of this, she experienced significant developmental delays. She began with the Early Intervention and later received special education services. She was diagnosed with an intellectual disability. Even so, my daughter always had two big dreams. First, she wanted to go to college, and second, she wanted to live on her own in an apartment with her friends. As parents, my wife and I naturally want to support our child’s aspirations, but we also have to be realistic. Knowing her disability, we didn’t think these dreams were possible, so we gently discouraged her. It felt like a “pie in the sky” -- nice to imagine but unlikely to happen. But this is where dreams became reality. I never thought this day would come. After eight years of high school, my daughter finally graduated and was accepted into the first-ever four-year program in California for students with disabilities at UC Davis (Redwood SEED Scholars Program). She lived in the dorms for two years and then in campus apartments with her friends, fully experiencing college life. I am so proud of her! She has grown by leaps and bounds in independent living such as, cooking, grocery shopping, doing laundry, managing money, riding her bike, and using Uber to get around. Over the past four years, her growth has been steady and incremental (not

overnight!). After all, how can anyone know their true abilities unless they are given a chance to grow with support? Allowing her to make mistakes and learn with guidance made all the difference. That is why it is called, “living and learning lab!” My daughter thrived in the UC Davis SEED Program, and we are incredibly grateful. She has now graduated, has a part-time job, and is living independently in an apartment in Davis with her friends from the program. We couldn’t be more proud of her. Her disability has never stopped her from reaching her full potential!

Thank You for Caring!

Written by Diane Sweet on December 7, 2025

If you're reading this right now, I wish I could hug you and tell you just how eternally grateful I am to live in a country who cares about its people, regardless of intellect, skill, background or ability. Thank you for passing and safeguarding the laws that keep this population safe, healthy and, most importantly, enable them to be productive citizens!!! THANK YOU, THANK YOU, for Home and Community-Based Services (HCBS). Our daughter was born with an unexplained intellectual disability. Despite her disabilities (intellectual, receptive, expressive & memory disorders), she has the strength of a warrior, the compassion of a nurse, and the demeanor of a diplomat. She has so many great things to contribute to society but needs the supports and the training & independent living skills necessary to do so. Without the services that HCBS offers through Medicaid, none of this could be a reality. We are extremely lucky that she was accepted into the University of California Davis Redwood SEED program (a 4-year, non-diploma college program focused on independent living skills for kids with intellectual disabilities - the only program like it in the entire west coast) this year. It has been utterly amazing - in just one quarter she has matured so much, has found friends who are just like her, she is growing, learning, developing and loving independent living just like all college students. Her writing has improved tremendously, her sense of self-care, her desire to be responsible, her drive to be a leader in the group, have all gained so much momentum. It has been awesome to witness in such a short period of time and we know it will lead to further advancements for her. While this population will never be able to work a 40-hour work week, they have a lot to contribute. Medicaid/Regional Centers/HCBS allows them to live & learn independently, an opportunity that would *never* have happened otherwise, without your help. THANK YOU FOR CARING!

My Daughter’s Richa’s story as an Intellectually Disabled Adult

Written by Seem Misra on December 7, 2025

Our daughter Richa Panda’s diagnosis of Microcephaly (small brain with simple gyral pattern) was confirmed in utero at 30 weeks of pregnancy, with a very poor physical and intellectual

prognosis. She was evaluated by Early Intervention Services in New Jersey and began therapy at four months of age. During the first three years of her life, she received 8–10 hours of therapy each week, including physical, occupational, speech, and developmental therapies. Alongside these services, we intentionally enrolled her in inclusive community programs such as Music Together and The Little Gym, which played a crucial role in building her confidence and social engagement. Before preschool, she also attended a state-sponsored social skills group to support her communication and emotional development. At age three, Richa started preschool in Special Education in Pleasanton, CA. From early childhood, she was remarkably social, eager to connect with others, and consistently hardworking. Throughout elementary, middle, and high school, she participated in both special education and inclusive general-education classes. These inclusive experiences were essential in helping her build confidence, emotional intelligence, self-advocacy, and meaningful friendships with typical peers. As she grew older, Richa received multiple supports through the Department of Rehabilitation and the Regional Center, which helped her strengthen daily living and independence skills such as managing her time, doing her laundry, walking to and from the bus stop, and navigating the Pleasanton Wheels bus system on her own. She also had an opportunity to work at the Dublin Wave waterpark, where she provided customer service in an inclusive, fast-paced environment. These experiences helped her learn patience, teamwork, professionalism, and how to handle real-life conflicts—skills she would not have gained in segregated settings. She demonstrated that, with the right support, she could thrive in environments shared with typical peers. After high school, she joined the school district's Adult Transition Program, which provided valuable exposure to minimum-wage job tasks. However, because the program was designed exclusively for adults with disabilities, her growth began to plateau. She was no longer challenged socially or academically, and she lacked opportunities to practice independence in real-world, age-appropriate environments. We realized that for her to progress toward a meaningful adult life—including independent living and gainful employment—she needed access to an inclusive program in a college setting that mirrored the experiences of her non-disabled peers. The Redwood SEED Scholars program has provided exactly what she needed: a structured, inclusive college experience where she can live independently, solve real-life problems, and learn alongside typical peers on a university campus. In this program, we have seen more growth in her independence, confidence, decision-making, and maturity within the last quarter than in the previous two years of the adult transition program. Being surrounded by peers her age, participating in campus life, and navigating daily routines without relying on us has accelerated her development in ways that traditional disability-only programs cannot. Key benefits for her include: 1. Independent Living Skills Managing her own schedule, meals, chores, and personal responsibilities Navigating campus safely and reliably Learning how to problem-solve without immediate parental support Building confidence in her ability to live on her own in the future 2. Inclusive Academic Experience Attending classes which builds academic stamina and social integration Learning how to advocate for herself in educational settings Experiencing the intellectual stimulation of a college environment 3. Career Exploration and Job Preparation In the next few quarters she will be

participating in supervised internships that expose her to real career pathways Understanding what types of jobs align with her strengths and interests Learning professional behavior in inclusive workplace settings Preparing for competitive, integrated employment—not just sheltered work 4. Social and Emotional Growth Making friendships with college peers Learning to collaborate, communicate, and resolve conflicts Strengthening her emotional regulation and resilience 5. Identity, Belonging, and Self-Worth Experiencing true inclusion—not as a visitor, but as a full member of her college community Building the same sense of belonging that her typical peers naturally experience Developing the self-confidence to imagine a future that includes independence, a fulfilling job, and meaningful relationships Why an Inclusive College Program Is Essential for Her Future For Richa, an inclusive college program is not simply an educational opportunity — it is the bridge between childhood dependence and a self-directed adult life. It offers her: A pathway to independent living Access to competitive employment, not segregated jobs The dignity of learning and living alongside typical peers The chance to build the adult life she deserves Programs like Redwood SEED Scholars unlock opportunities that traditional special-education and segregated transition programs cannot provide. They help young adults with intellectual disabilities learn how to navigate life the same way other young adults do: through lived experience, inclusion, community, and meaningful expectations. This inclusive college experience is giving Richa every opportunity to reach her full potential — to live independently, build a career she enjoys, and achieve financial and personal independence.

HCBS impact on inclusive college

Written by Simon Tam on December 7, 2025

My son Kurtis is attending the UC Davis Supported Education to Elevate Diversity (SEED) program. It is an inclusive college program for individual with disabilities. Kurtis has mild to moderate intellectual disabilities throughout his life. He attended special education class from kindergarten to high school. Therefore he had little interactions with main stream students his age and exposure to the regular academic learning. Ever since he joined the SEED program it opened up a whole new world for him. Because he has no siblings and did not know how to make and keep friends, he was very isolated and kept to himself in his room to play video games for hours before joining the program. He showed signs of moderate anxiety and OCD. He received medications and therapy but the positive results were somewhat limited. After joining the program he made a lot of friends and connections both inside and outside of his cohort. He is now more engaged with his new environment and becomes more confident and focused. His anxiety and OCD are now way better than before. One important point I like to highlight. Often we focus on the impact Community-Based Services (HCBS) have on the individual with disabilities. Let's not forget the ripple effect it has on the family members directly supporting the individual. An individual progressing from dependent to self-reliant is transformative to him/her as well as the parents, brothers, sisters, grandparents and so forth. The positive influence is

immense and profound. I found myself to be more engaged in the society and become more productive knowing that there is a hope and better future for Kurtis. In short, HCBS funding invests in an individual as well as the entire close community surrounding the individual. I encourage the measure of success should take into that fact into consideration.

Living in my apartment

Written by Kiara Picchi on December 7, 2025

I am Kiara Picchi. I have an Intellectual Disability and I am Autistic. I go the Redwood SEEDs program at UC Davis California. It is an inclusive college program. Part of the program is living in the apartments. I have learned to wash my own dishes, wash my own clothes, clean up after myself, and cook my meals with a mentor. I know now how to live on my own and go to class independently. Living in the apartments has been fun and it makes me feel independent. I would never have never learned these skills without this program and the mentor's support. Thank you for listening to my story. From Kiara Picchi

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Giving Students with Disabilities a Future Through Inclusive Education

Written by Raylene Cornelio on December 7, 2025

Dear Senator, My name is Raylene Cornelio, and I am a parent of a student with disabilities. My son, Carlo, 22, is a freshman in the Redwood SEED Scholars Program at UC Davis. Carlo has Epilepsy and an Intellectual disability. Because of this program, he is learning how to live more independently, build confidence, and work toward a meaningful future. Programs like Redwood SEED are life-changing for students like my son. They provide academic, life skills, and independent living support that traditional college programs do not offer. Through Home and Community-Based Services (HCBS) funded by Medicaid and supported by California’s Regional Center system, Carlo receives the support he needs to live, learn, and grow alongside his peers. Before this program, I was worried about Carlo’s future — where he would live, how he would work, and how he would be part of his community. Now, because of this opportunity, I see him becoming more independent, more confident, better at navigating his everyday life, and more hopeful. Many inclusive college programs are short-term and do not offer independent living supports. Programs like Redwood SEED are rare and essential. I respectfully ask you to support policies and funding that protect and expand programs like this so more students with disabilities can have the same opportunities as my son Carlo. Please continue to support Medicaid HCBS services and inclusive post-secondary education programs. These services do not just help students with disabilities — they give families hope for their children’s futures. Thank you for your time and your service. Sincerely, Raylene Cornelio Carlo's mother

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Only

Written by Chris Fillius on December 7, 2025

I am writing to urge you to protect funding for Home and Community-Based Services (HCBS) through California's Regional Center system. My son has a chromosomal disorder and intellectual disability and has struggled throughout school—both academically and socially. For years, he felt isolated and unable to fully participate in life around him. Everything changed when he began attending the Redwood SEED Scholars Program. For the first time, he has found a community where he belongs. He is busy, engaged, and genuinely happy—all new experiences for him. Most importantly, the program's goal is to help him live independently when he finishes, giving him the foundation to build a meaningful life on his own terms. What makes this program possible is HCBS funding through Regional Centers, which supports the independent living component and mentors. This is extremely rare—90% of inclusive college programs are only two years long and offer no independent living opportunities at all. Without this funding, programs like Redwood SEED Scholars cannot exist, and young adults with disabilities have nowhere to turn when they age out of school services. These services are lifelines for families like mine. I respectfully urge you to protect Regional Center and HCBS funding in upcoming budget decisions. Thank you for your consideration. Sincerely, Chris Fillius

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gretchen’s story about UC Davis

Written by Gretchen Wahle on December 7, 2025

before I knew about the program I started at UC Davis my mom and Beth helped me to be better at Becoming independent on my own And got an email from them and I was really excited and my family was excited for me and I had the best experience before I knew about the program and when I went to camp I had the best experience it was really fun and Beth and Sarah really helped me through the years but they also cared and about me and they also wanted wants best for me but I am also very lucky to be in this program to have them into my life before I knew about the program I knew Beth before the program started and I am glad that I did and I am A junior in the program and I want to be able to live independently on my own and to support myself in I am very confident in this

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kirra’s life story

Written by Kirra Troeger on December 7, 2025

when I first found out that I got into Davis I was in class and I got an email saying that I got in I was so excited and shocked. I had showed the email to my aid and she was so happy for me. when I finally went to Davis I thought it was so big and a lot of bikes but there was more then

just that for me. I met a lot of new people that became my friends in the program that I am in now, there has been a lot like I have a job at the local market where I help with the food and at the cashier. I have worked on my independent skills and my way around Davis. I have learned life-long lessons this program I just love everything here at Davis. Beth and Sarah are amazing and they did a lot for me. I would want to thank them for all they do for me. this program is not just a big group of friends they more like my family. It's like a party everyday with them.

Shanthi's Experience at the UC Davis Redwood SEED Program

Written by Krishna and Purush Rao on December 7, 2025

December 7, 2025 Dear Members of Senate Committee on Aging, I am reaching out to you today to share our daughter's story. Her name is Shanthi and she is 22 years old and has Down's Syndrome. She graduated from high school and then took classes at our local community college for two years. While Shanthi was gaining academically, she was still living at home with us. Shanthi was socially isolated from her community and was not gaining the independent living skills she needed to live and work independently. After much research, we were thrilled when we learned about the UC Davis Redwood SEED program. It is a four year residential college program that helps students with intellectual disabilities learn independent living skills and job skills. Since enrolling this past fall, Shanthi lives on campus, attends classes and is learning valuable skills with support from peer mentors and staff. She is able to live in and maintain her dorm room, navigate the campus to get to the dining halls and classes, and do all of this in a timely manner. We look forward to seeing Shanthi grow over the next three years. And look forward to the day she will be an independent and productive member of her community. Sincerely, Krishna and Purush Rao

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Support Families With Disabilities

Written by Alan Fernandes on December 7, 2025

To: The Honorable Susan Collins, Chair The Honorable Bob Casey, Ranking Member U.S. Senate Special Committee on Aging G-31 Dirksen Senate Office Building Washington, D.C. 20510 Subject: The Urgent Need to Invest in Inclusive Postsecondary and Employment Programs for Adults with Disabilities Dear Chair Collins, Ranking Member Casey, and Distinguished Members of the Committee, I am writing to express my strong support for programs, such as the UC Davis Redwood SEED (Supported Education to Elevate Diversity) Scholars Program, that are designed to significantly improve the educational, employment, and independent living outcomes for adults with intellectual disabilities. I urge the Senate Special Committee on Aging to champion legislation and funding to support the expansion of this essential model across the nation, which will ultimately enhance the lives of millions of families and strengthen the American economy. The Vital Role of Inclusive Programs Programs like the

Redwood SEED Scholars initiative address a critical gap in our education and workforce development systems. This four-year residential, inclusive college program provides young adults with intellectual disabilities the opportunity to: * Live on campus and engage in social inclusion with typical peers. * Take foundational, customized courses alongside credit-bearing university classes. * Gain multiple paid, integrated employment experiences leading to competitive employment. * Develop crucial skills in self-determination and independent living. Currently, employment rates for working-age adults with disabilities lag significantly behind those without disabilities. Furthermore, a substantial majority of adults with intellectual disabilities live in poverty. Programs like Redwood SEED are a powerful antidote to these troubling statistics, offering a pathway toward economic independence and full social participation. Improving Quality of Life for Millions of Families. The benefits of these programs extend far beyond the individual participant. When an adult with a disability secures competitive, integrated employment and is able to live more independently: * The entire family unit benefits: Financial stress is significantly reduced, and family members, including aging parents and guardians, gain greater peace of mind knowing their loved one has a stable, fulfilling future. * Caregiver burden is alleviated: Family members, many of whom are older adults themselves, can spend less time and energy providing intensive daily support and more time focusing on their own well-being and careers. This is directly relevant to the Committee's focus on aging and caregiver support. * Self-determination is realized: The dignity, self-esteem, and quality of life for the adult with a disability are dramatically elevated through meaningful work and community engagement. A Sound Economic Investment Investing in the expansion of inclusive postsecondary and employment programs is not merely a social expenditure; it is a strategic economic investment with substantial returns. Increasing employment among the disability community will: * Boost the Tax Base: More employed adults contribute through income and payroll taxes, increasing federal and state revenues. * Reduce Reliance on Public Benefits: As individuals move into competitive employment, their dependence on programs like Supplemental Security Income (SSI) and Medicaid decreases, generating significant savings for the taxpayer. * Strengthen the Labor Market: These programs effectively train a capable and underutilized segment of the population, helping to alleviate labor shortages and adding millions of dedicated workers to the American workforce. According to data, if individuals with disabilities experienced the same employment rates as those without disabilities, millions more workers would be contributing to the economy. Conclusion The UC Davis Redwood SEED Scholars Program is a testament to the transformative power of comprehensive, inclusive education and employment models. I urge the U.S. Senate Special Committee on Aging to recognize the critical role these programs play in supporting aging caregivers, empowering adults with disabilities, and strengthening our national economy. By investing in the expansion of this successful model, we can improve the lives of millions of Americans and foster a more equitable, productive future for all. Thank you for your time and consideration of this urgent matter as this program has made an enormous impact on our family. Sincerely, Alan Fernandes

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My Independent living story

Written by Bryan Ma on December 7, 2025

I'm 22 years old and I have been diagnosed with ataxic cerebral palsy since birth. Currently I am a student in the Redwood Seed Scholars program at UC Davis. I have had the opportunity to learn independent living skills like cooking, keeping my apartment clean, and learning to get along with my roommates. Every week I go to Trader Joe's and shop for food that I can cook. For the last 3 years I have lived in a college dorm room and in an apartment. I am able to keep my own schedule and get to my classes and my places of employment on time. I am also keeping track of my budget for my living expenses. Based on these experiences, I feel confident that I can live independently with support after I graduate next year. I plan to continue living independently with friends in an apartment in Davis California. I also want to get a job and contribute to my community.

Hello, I'm Alyssa Ba

Written by Alyssa Bacon on December 8, 2025

Hello, I'm Alyssa Bacon a Senior in the Redwood SEEDS Scholars Program. This program has helped me in many ways. In my first two years in the dorms it helped me with learning how to live independently and doing stuff like laundry on my own. Another thing was making a lot of friends and hanging out with friends and the mentors were a great help in the dorms by helping us get comfortable living with roommates and others in the dorms, communicating with friends, others in the dorms and professors and they were always there if I needed them. In my second year in the dorms they showed us the way to Trader Joe's, taught us shopping and how to follow a recipe and started Cooking with Sophomores so when we got to the apartment for the third year, we could cook on our own or together. Also, we learned how to take the bus to go to Target and around Davis so we can get stuff we need for like laundry detergent and different stuff. Then, when we got into the apartments which was off campus we started paying the electric bill. At first it was difficult but we got through it. We cooked, shopped and did everything independently. Also it helps me find jobs that I like to do and actually get paid and learn how to do that independently. Right now after the Redwood SEEDS scholars program I'm going to be living in the Identity's with some of the other RedWood SEEDS scholars and being independent there. Also, hopefully keep my jobs on campus and maybe get an off campus job in Davis too. Our daughter is a senior in the Redwood SEEDS program. The program provides support in all areas towards living independent productive lives in the community. In her 4 years in the program she has learned so much. In the first 2 years she lived in the dorms with all of the other UCD students. She was given the invaluable opportunity to learn to live in a community with other young college students. She learned communication skills, how to share community space

including living and getting along with other scholars and roommates and how to be responsible for herself. Mentoring assistance was key to her learning these life skills. In addition the mentors were there to support the scholars with academics: studying and homework assistance, health and wellness, support with employment and social inclusion. This mentoring continued into her next 2 years while living in an apartment with roommates. She is responsible to paying her utility bill, cooking and nutrition, laundry, and keeping the apartment clean and working. Her responsibility and independence has increased each year as has her confidence in herself and her ability to live in the community. Her confidence and our observation of her tremendous growth has given us the confidence that she is ready and capable of living on her own next year after she graduates from the program. With all the Redwood SEEDS program has provided to the Scholars and our daughter we are confident about her ability to live a full involved life while contributing to her community and enjoying a safe, fulfilled life.

Redwood seed scholars

Written by Kumar Samuel on December 8, 2025

I feel like I've gotten to do so many things and I feel like a big community to the redwood seed scholars program. I've grown into and independent man

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From Fragile X Diagnosis to UC Davis Success

Written by Sanji Yogasundram on December 8, 2025

My son is part of the Redwood Seeds program at UC Davis. When he was younger, we were told he would never be in a regular classroom or go to college. We were told to limit our expectations. But he has proven every one of those predictions wrong. He has just finished his fourth year at UC Davis, and each quarter he has taken a credit-bearing class alongside neurotypical peers. Even more meaningful, he has built real friendships, learned to live independently — first in the dorms and now in apartments — and has held paying jobs. These are milestones we never dared to imagine years ago, when we first heard his Fragile X diagnosis. What we once feared might not be possible has become his everyday reality. As he prepares to graduate, he has chosen to stay in Davis another year to live with six other young men with intellectual disabilities. He won't have the structured supports of Redwood Seeds anymore, but I truly believe the program has equipped him with the confidence, skills, and independence he needs to thrive. We are incredibly proud of how far he has come with the support of his teachers, therapists, doctors, friends, and family; as well as the support of Regional Centers and the DOR. We are even more excited to see what he will do next.

My son who has a gen

Written by Allison Gray on December 8, 2025

My son who has a genetic disorder and intellectual disability relies on Home and Community-Based Services (HCBS) for the independent living skills component of his inclusive college program (Redwood SEED Scholars, UC Davis), which is helping him to build the skills and tools he needs to live independently in his community. In just his first quarter of getting to live in the dorms, he has developed foundational skills necessary for success in an independent living setting and has the support required to continue to learn and grow on campus. Inclusive college programs are essential to the future of students with intellectual disability. HCBS must be protected and preserved so that students like my son have the opportunity to develop and thrive and contribute to society. Thank you, Allison

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Carlo redwood seed scholars program living independently

Written by Carlo Cornelio on December 8, 2025

My story about me getting to live in the dorms means I get to live independently, figure out on my own and do my laundry, learn to learn new things and navigate better around the city, campus better, do my hygiene on my own , practicing resume writing, budgeting my money on my own , doing my laundry and showering on my own , always on time, there is a check in person day and night to check up on me how is my sleep, hygiene laundry and cleanliness in the dorm, I get to budget my own money, save my money and learning how to spend my money wisely

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The LGBTQIA+ community

Written by Gary Oey Steven on November 21, 2025

The LGBTQIA+ community is a community which is diverse, equitable, inclusive, and affirming to all members and allies from diverse races, religions, ethnicities, national origins, socioeconomic statuses, political beliefs, genders, gender identities, sexual orientations, abilities, mental health conditions, and all other categories. With that being said, LGBTQIA+ people with Autism or disabilities get barred from LGBTQIA+ spaces or are restricted from accessing certain LGBTQIA+ spaces. Around the United States, which includes LGBTQIA+-affirming cities like New York, Chicago, San Francisco, and Los Angeles, LGBTQIA+ people with Autism face barriers to LGBTQIA+ events, communities, and resources, due to lack of education and development of understanding what Autism is in the LGBTQIA+ community or vice versa. Sadly, gender-diverse people with Medicaid, SSI, and certain benefits such as OPWDD services, face hardships to accessing gender-affirming care and other related support services. When discussing Autism organizations and disability agencies, such as OPWDD, LGBTQIA+

resources can be vague and nuanced. Certain disability entities, especially most advocacy groups, are highly vocal on LGBTQIA+ representations, while certain disability entities, especially some traditional clinics, are still welcoming to the LGBTQIA+ community, but may not have enough understanding on LGBTQIA+ identities in people with disabilities, and may not always be able to provide LGBTQIA+-affirming resources to LGBTQIA+ people with disabilities. It is important that large organizations like ASAN and the United States Congress work harder to make LGBTQIA+ awareness, communities, and resources more accessible to people with Autism and disabilities.

All labor is valuable

Written by AJ Cho on November 22, 2025

I am not disabled myself nor do I currently rely on independent living services. However, I have seen people playing games and creating music live on platforms like Twitch because their chronic illnesses and complex health needs make conventional wage labor impractical, even dangerous, for them. I am extremely worried that chronically ill, disabled, elderly, and neurodiverse people will be denied health care simply because their conditions don't align with the unaccommodating requirements of the conventional workforce.

HCBS is a blessing.

Written by Jada Thompson on November 23, 2025

HCBS is a blessing.

Seven months in the hospital

Written by Rebecca Carta on November 24, 2025

I spent several months in the hospital when I was born because I have a disability called Spina Bifida. I had several leg surgeries and a spine surgery and shunt surgery where had to put a shunt in my head, I also have hydrocephalus.

Brian Habermehl

Written by Brian Habermehl on November 24, 2025

MY LIFE Matters

The Independence of Peter

Written by Peter Allmond Evans on December 7, 2025

My story about me getting to live in the dorms means I get to live independently and meet people that I didn't know since I was 8 months old. I get to do whatever I want. I learned how to process my emotions a little bit better. I do my laundry, learning how to live with other people. Learning these skills have helped me learn how to navigate better. I learned how to walk around a city the whole campus by myself.

My life at UC Davis

Written by Brian Brazil Fluitt on December 7, 2025

My name is Brian Brazil Fluitt, and I am a freshman student in the UC Davis Redwood SEED Scholars Program. I am writing to share my story because this program has made a life changing difference for me. I was diagnosed with autism when I was three years old. Growing up, many things did not come easily for me. I had to work harder than other kids to communicate, to understand things, and to be included. There were times when people doubted what I could do. But I never stopped trying, and I always hoped that one day I could have the same opportunities as everyone else. The Redwood SEED Program helped make that hope real. For the first time, I feel like I truly belong in a college community. I am taking real classes, learning new skills, and proving to myself that I can do more than I ever believed. The teachers and mentors here see my potential and support me in ways that help me grow every day. One of the most important parts of this experience has been living in the dorms on campus. Living in the dorm has helped me become more independent and confident. I am learning how to take care of myself, manage my own schedule, communicate with my roommates, and be responsible for my daily life. These may seem like simple things, but for me they are huge steps and I am proud of myself for them. Living in the dorm has also given me something I dreamed about for a long time: friends and a sense of community. I have people around me who understand me, include me, and support me. I feel part of something bigger, and that feeling has changed my life in a very real way. Programs like Redwood SEED open doors for students with intellectual and developmental disabilities doors that were closed for many years. They give us opportunities to learn, to grow, and to contribute to our communities. They give us a chance to build real futures. I am asking for your continued support for inclusive higher-education programs in California. Your support helps students like me live more independent lives and reach our full potential. Thank you for your time, for listening to my story, and for all you do for the people of California. Sincerely, Brian Brazil Fluitt

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On my own

Written by Alison Mills on December 3, 2025

I have been seriously mentally ill for over thirty years. I started out in my home county of San Mateo. I was empowered and educated by many of the programs & services and became a leader for awhile. I was able to have section 8 and the benefit of people that were like minded in that all of us clients had something to offer to the community we had. We were educated empowered and respected for what we had to offer. I left my home where I felt supported and safe. They had emergency plans on what to do with all the clients if there was a wide spread epidemic way before Covid. Emergency supplies of meds in case none were available and up to date. I knew probably from participated in self help and the mental health board and state wide. I am old now and the county I am in now has barely enough to provide for all the existing clients. It is just not anything like being in a wealthy county. I struggle with money to fix my home. Buying my food. I pay my bills first and make do with the rest. Life is hard enough but to have to worry about everything else plus being seriously mentally ill. People have taken advantage of my status like realtors selling me someone else's problems. I totally feel like I am truly alone. I'm not sure what kind of stories you wanted but I endure the struggles and I am a better person from them. Not ever being taken seriously in the world is a hard pill to take. Alison B. Mills

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Life as an autistic male

Written by Joseph Carpenter on November 24, 2025

My name is Joseph Carpenter and I am Autistic. I live alone. I have a cat named Princess. I work only 4 hours at Burger King in Sunbury which I walk to. My life was an adventure. I was diagnosed at age 6, before that I was always bullied. I felt that I was the problem. But I was wrong, They wanted me to stop making animal noises or roars and I felt sad. I need support to live my life to the fullest in my own home. Thanks to that support I live my life, my way, making my own choices. Without funding from Medicaid my life could be sad.

Living in a world you are constantly misunderstood or not heard

Written by Teresa Corcoran on November 24, 2025

I am Hearing impaired. It makes it very difficult to communicate and understand what is happening around me. I need help completing my daily living activities because of my hearing my speech is difficult for others to understand what I am saying. With the support of my staff I am able to communicate with others and have a sense of belonging. My support staff makes it possible for me to participate and be a part of my community.

My Story

Written by Amy Michaels on November 24, 2025

I am 43 with Down Syndrome. I am a different person. I got picked on a lot growing up. They made fun of me because of my disabilities. I tried to fit in. My support staff is necessary so I can get out and about and participate in community activities. Medicaid makes all that possible.

Story of Brandy Torio

Written by Brandi Torio on November 24, 2025

My name is Brandy. I live in a lifesharing home. I need help cooking, cleaning and bathing. My family living provider helps me by cooking meals with me, helping me bathe daily, and support picking out my clothes. I have Cerebral Palsy and spina bifida. I enjoy baby dolls books and completing puzzles. I go out with direct support staff Monday through Friday. My DSP takes me out in the community. I participate in self advocacy class, money management, and book clubs. I enjoy spending time with my friends. i also need support with my financials and traveling. I am unable to drive or make good decisions on my own. My supporters help me learn and respond in the correct ways.

Pahrump and lack of care for seniors

Written by Catherine Salmonwolff on November 25, 2025

I have been thinking of this for 5 day but need to share my story. Pahrump has 1/3 percent seniors but is not setup for us. I went to my doctor's and parked in handicap and when I got out I went to the sidewalk which I had to put my walker on and then tried to balance myself as I stepped up but fell on the sidewalk. I told my doctor and he wanted me to get an x-ray but his tech wasn't there so told me to come back another day. So I went out to my car and this time had to put my walker on the street then step down when I fell again and landed on the street. I ended up in the hospital and asked every doctor, nurse and even cleaning people for a social worker to help me get the things I need like a wheelchair ramp so I can leave the house to go to the doctors. Unfortunately 3 months later I still don't have a social worker. I am so tired and ready to give up on life. Thanks and I hope all of you have better luck. Cathie

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My life in UC Davis

Written by Jaylen Parks on December 7, 2025

When I came to UC Davis in my 1st year I started feeling homesick because I miss my family and friends and made some bad choices. But the Mentors got me together and showed me that

enjoying college life is fun I hang out with my friends on campus we go to football, volleyball, and basketball game, going to target, karaoke, movie night, bowling, working out at the ARC, and heading to the rec pool for a swim on hot days. In the dorms I do my laundry, vacuum the floor, and take out the garbage and sometimes on weekends I hang out with my family. During my 2nd year I took African American Studies to support my cultures. I worked at the Employment Disability Center as a app tester we go through some apps to help students with intellectual disability who have a hard time of hearing, seeing, and saying on the computer, and laptops. In the spring quarter Mrs. Beth showed us the apartment at the colleges that will be living in our 3rd & 4th year. During my 3rd year in Davis I've lived in the apartment with Kai Gardizi and Ryan Fitch we do the dishes, cook dinner, do the dishes and I was in charge of paying the bill. I even make either Vanilla, Chocolate, and Strawberry Cake for the Scholars birthday, and potluck and make Peanut Butter and Jelly Sandwiches for the homeless shelter. I led the target run on Saturday, showed the freshman around campus and I not only work at the Students Disability Center I also work at the Mail Distribution Center, During my 4th year in Davis I live with Matthew Mokski and Jared Miller, during my last year in Davis I didn't made one incident I just stayed calm and cool like ice. When the Redwood SEED Scholars Program graduation came I wasn't sure what I was feeling but when Black Graduation arrived I was nervous but I took some deep breath and graduated with honors, then I helped out during summer camp for the new freshmen from 8/17/2025 to 8/23/2025. Now i'm at home searching for a job. Now i'm starting at Oak and Cedar community center on 21st Street in Sacramento California tomorrow.

Life changing growth

Written by Erica Conway on December 7, 2025

My name is Erica Conway and my daughter attends the UCDavis Redwood SEED Scholar program. This program has far exceeded my expectations for my daughter. As a junior, she is learning to live independently. She cooks, cleans, navigates the community on her bike and holds two jobs while attending classes at UCDavis. This program and other programs like it are essential to allow people with intellectual disabilities to live as independently as they can in a social community. They will in turn be less dependent on our social security system. If we put the money in today, it will save the government money exponentially in the future plus our kids have a much higher quality of life. Everyone deserves to reach their full potential. The SEED program funding is critical for these young adults. Don't take away their dreams!!



Statement for the Record

U.S. Senate Special Committee on Aging–

December 3, 2025 – Hearing on Aging in Place: The Impact of Community during the Holidays

Submitted December 8, 2025

Prepared by Caring Across Generations

228 Park Avenue South, Suite 93898
New York, NY 10003

Caring Across Generations Statement for the Record
U.S. Senate Special Committee on Aging Hearing on Aging in Place: The Impact of Community during the Holidays

12.08.25

Dear Chairman Scott, Ranking Member Gillibrand, and Members of the U.S. Senate Special Committee on Aging,

Caring Across Generations is a national organization of family caregivers, care workers, people with disabilities, and aging adults working to transform the way we care in this country so that care is accessible, affordable and equitable— and our systems of care enable everyone to live and age with dignity. We appreciate the opportunity to submit a written statement for the record on the vital importance of aging in place and community living for older adults, people with disabilities, their families, and the family caregivers and direct care workers who provide this critical care.

Every person will at some point either give or receive care – for their children, an aging or disabled family member, or while experiencing disability or becoming older themselves. In this country, 105 million people – or 40 percent of all adults – are family caregivers for older adults or people with disabilities.[1] Every day, 10,000 Americans turn 65 years old, and the number of older adults over 85-years-old is expected to more than double by 2040.[2] More than 1 in 4 people in the U.S. have disabilities, and across the country, more than one in five adults receive ongoing support with every day activities, like bathing, dressing, and taking medications.[3] Nearly 5 million people are direct care workers, providing care in homes and communities that enables living and aging with dignity.[4] Aging and disability is a fundamental part of the fabric of our daily lives.

Medicaid makes community living and aging in place possible, but the system is fragile.

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[1] Rajeev Ramchand, et al. "America's Military and Veteran Caregivers Hidden Heroes Emerging from the Shadows," RAND, Sept. 24, 2024. https://www.rand.org/pubs/research_reports/RRA3212-1.html

[2] America Counts Staff, "2020 Census Will Help Policymakers Prepare for the Incoming Wave of Aging Boomers," United States Census Bureau, Dec. 10, 2019. https://www.census.gov/library/stories/2019/12/by-2030-all-baby-boomers-will-be-age-65-or-older.html; Administration for Community Living, U.S. Department of Health and Human Services, "2023 Profile of Older Americans," May 2024. https://acl.gov/sites/default/files/Profile%20of%20OA/ACL_ProfileOlderAmericans2023_508.pdf

[3] Center for Disease Control, "Prevalence of Disabilities and Health Care Access by Disability Status and Type Among Adults," Apr. 11, 2025. https://www.cdc.gov/disability-and-health/articles-documents/disabilities-health-care-access.html; Ashley Kirzinger, Audrey Kearney, Mellisha Stokes, et. al, "KFF Health Tracking Poll - October 2021: Home And Community Based Services And Seniors' Health Care Needs," Kaiser Family Foundation, Oct. 15, 2021. https://www.kff.org/report-section/kff-health-tracking-poll-october-2021-home-and-community-based-services-and-seniors-health-care-needs-findings/

[4] PHI, "Direct Care Workers in the United States: Key Facts," Sept. 2025. www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-2025

Choosing to live life in the community is a fundamental civil right for people with disabilities and older adults, and aging and disability care in homes and communities is what makes that civil right accessible. The vast majority of people – including 94 percent of older adults and 89 percent of people with disabilities[5] – would prefer to live and age in their own homes and communities. In order to live and age with dignity in their homes and communities, people with disabilities and older adults rely on home and community-based services (HCBS) to meet their needs, most often provided by direct care workers, family caregivers, or both. Aging and disability care in homes and communities improves health outcomes, life satisfaction, and increases the ability to perform daily living tasks independently.[6] Receiving aging and disability care upfront when need arises also decreases the risk of long periods of institutionalization in nursing homes or other facilities and reduces the risk of reinstitutionalization.[7] For working age people with disabilities, Medicaid HCBS can provide supported employment, helping people with disabilities obtain and retain work with competitive wages, leading to better health outcomes and higher earnings for those enrollees, lower costs for state Medicaid agencies, and increased profits and higher employee retention for employers.[8] Additionally, people with disabilities and older adults who receive supports to transition out of institutions and into their communities report higher quality of life and life satisfaction.[9]

Under the ADA and the *Olmstead v. LC* Supreme Court decision, states are required to provide services in the most integrated setting possible, rather than unnecessary segregated settings.[10] Medicaid HCBS is the primary tool available for states to comply with this integration mandate.[11] For the millions of people seeking aging and disability care in their homes and communities, Medicaid is the only insurance that meaningfully covers long-term care, as private insurance is too expensive or limited in scope and Medicare does not cover long-term care.[12] Medicaid pays for more than 70 percent of all spending on home and community-based services

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[5] Data for Progress & Caring Across Generations, "Voters in Every Congressional District Oppose Cuts to Medicaid," Apr. 23, 2025.
https://www.dataforprogress.org/blog/2025/4/23/voters-in-every-congressional-district-oppose-cuts-to-medicaid
[6] National Council on Disability, "Strengthening the HCBS Ecosystem: Responding to Dangers of Congregate Settings during COVID-19," Nov. 16, 2022.
https://www.ncd.gov/assets/uploads/reports/2022/ncd_strengthening-hcbs-ecosystem_508.pdf
[7] Kate Stewart & Carol V. Irvin, "Does Early Use of Community-Based Long-Term Services and Supports Lead to Less Use of Institutional Care?," Mathematica Policy Research, Accessed Dec. 3, 2025 at
https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/hcbsasadiversiontoiltc.pdf
[8] Katherine Hayes et. al, "Improving Opportunities for Working People with Disabilities," Bipartisan Policy Center, Jan. 2021.
https://bipartisanpolicy.org/wp-content/uploads/2021/01/BPC_Health_Medicaid-BuyIn_Report2021V4.pdf
[9] Julie Robison et. al, "Connecticut's 'Money Follows the Person' Yields Positive Results For Transitioning People Out of Institutions," Health Affairs, Oct. 2015,
https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2015.0244?journalCode=hlthaff
[10] U.S. Department of Justice, "Statement of the Department of Justice on Enforcement of the Integration Mandate of Title II of the Americans with Disabilities Act and Olmstead v. L.C.", Feb. 28, 2020.
https://www.ada.gov/resources/olmstead-mandate-statement/
[11] Centers for Medicare & Medicaid Services, "State Medicaid Director Letter #20-003 Re: Home and Community-Based Settings Regulation – Implementation Timeline Extension and Revised Frequently Asked Questions," Jul. 14, 2020, https://www.medicaid.gov/Federal-Policy-Guidance/Downloads/smd20003.pdf
[12] Congressional Research Service, "Long-Term Services and Supports: History of Federal Policy and Programs", Dec. 20, 2023. https://crsreports.congress.gov/product/pdf/R/R43328

(HCBS), filling a critical gap.[13] Across the country, 7.8 million older adults and people with disabilities rely on Medicaid for HCBS.[14] Medicaid dollars are also used to pay direct care workers and 11.2 million paid family caregivers, providing critical care that enables community living and aging in place.[15] Access to Medicaid HCBS enables older adults and people with disabilities who need care and their families to choose what is right for them and their unique needs.

The long-term care system is already fragile, with more than 600,000 people on HCBS waiting lists, people forgoing care because of the astronomical cost, and a 50-state shortage of well-paying jobs for direct care workers resulting in inadequate access to care. People turning 65 already have a nearly 70 percent chance of needing long-term care, and approximately 20 percent will need more than five years of services.[16] More than half of people who currently receive Medicaid HCBS are under age 65, and many will need care for years or decades.[17] Nearly one in five adults say they or a family member need either new or additional paid support to meet their needs[18], and more than 50 percent of people who need care report difficulty in finding help.[19] Even for those with Medicaid HCBS, nearly one-third of enrollees report their services do not fully meet their goals and needs.[20] Unmet aging and disability care needs consistently worsen health outcomes for older adults and people with disabilities who need care, and going without care can mean not being able to get out of bed or into the community, increased falls, missed appointments, lack of adequate nutrition, and increased hospitalization, institutionalization, and mortality.[21] The current patchwork system forces many older adults and people with disabilities to become impoverished to access care through Medicaid, enter institutional settings despite preferring to live and age at home, turn to undersupported family caregivers, or go without care entirely.

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[13] Priya Chidambaram & Alice Burns, "10 Things About Long-Term Services and Supports (LTSS)," KFF, Jul. 8, 2024. https://www.kff.org/medicaid/10-things-about-long-term-services-and-supports-ltss/

[14] Caitlin Murray, et. al, "Trends in Users and Expenditures for Home and Community-Based Services as a Share of Total Medicaid LTSS Users and Expenditures, 2022," Mathematica & Center for Medicare & Medicaid Services, Aug. 29, 2024. https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-rebalancing-brief-2022.pdf

[15] Congressional Research Service, "Long-Term Services and Supports: History of Federal Policy and Programs", Dec. 20, 2023. https://crsreports.congress.gov/product/pdf/R/R43328; AARP & National Alliance for Caregiving, "Caregiving in the US: Research Report," Jul. 2025. www.aarp.org/content/dam/aarp/ppi/topics/ltss/family-caregiving/caregiving-in-us-2025.doi.10.26419-2fppi.00373.001.pdf

[16] Administration for Community Living, U.S. Department of Health and Human Services"How Much Care Will You Need?", February 18, 2020. https://acl.gov/ltc/basic-needs/how-much-care-will-you-need

[17] KFF, 2023, "Who Uses Medicaid Long-Term Services and Supports?" Dec. 14, 2023. https://www.kff.org/medicaid/who-uses-medicaid-long-term-services-and-supports/

[18] Ashley Kirzinger, Audrey Kearney, Mellisha Stokes, et. al, "KFF Health Tracking Poll - October 2021: Home And Community Based Services And Seniors' Health Care Needs," Kaiser Family Foundation, Oct. 15, 2021. https://www.kff.org/report-section/kff-health-tracking-poll-october-2021-home-and-community-based-services-and-seniors-health-care-needs-findings/

[19] KFF, 2023, "The Affordability of Long-Term Care and Support Services: Findings from a KFF Survey," Nov. 14, 2032, https://www.kff.org/health-costs/the-affordability-of-long-term-care-and-support-services/

[20] Natalie Chong et. al, "The relationship between unmet need for home and community-based services and health and community living outcomes," Disability and Health Journal, April 2022. https://www.sciencedirect.com/science/article/abs/pii/S1936657421001953

[21] Ibid.

Aging in place and community living are already at risk. Gutting Medicaid will cause the fragile care system to fail completely for people with disabilities and older adults who rely on aging and disability care at home and the family caregivers and direct care workers who provide critical assistance.

When Medicaid funding is limited or reduced – as it was through H.R. 1 – states are forced to cut spending by eliminating services, including reducing hours of services, limiting eligibility, or reducing provider rates, including rates for direct care workers.[22] States must provide services to all people enrolled in Medicaid who qualify for mandatory services, including nursing facility care.[23] Long-term care in homes and communities, however, are optional for states to provide, allowing states to limit how many people can receive care even when individuals are eligible, and leaving HCBS on the chopping black when states must pare back Medicaid funding.[24] More than half of state optional spending is spent on HCBS.[25] Historically, when federal Medicaid funding to states is reduced, every single state cuts funding for home and community-based services.[26] Decreasing the number of participants and per-participant spending results in fewer hours of care for people who need care most, and service reductions and the reduced number of people enrolled greatly increased the waiting lists for the HCBS programs.[27] Without Medicaid HCBS, people with disabilities and older adults who need care to remain in their homes and communities have no other options, putting immense pressure on states. For example, in California, cutting HCBS recipients by 3 percent (a significantly smaller cut than 2010-2012) would cost the state $57 million in just the first year after cuts due to higher cost of nursing facility care for people who lose HCBS access.[28] If more than 3 percent of HCBS recipients lose HCBS, California would have too few beds to meet the higher demand.[29] Cutting HCBS funding results in decreased care hours, making individuals more likely to end up in costly institutional

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[22] Brit Vanneman, Elizabeth Zirker, & Geraldine Doetzer, "OBBBA Harms People with Disabilities: Limits on State Directed Payments," National Health Law Program, Nov. 19, 2025, https://healthlaw.org/resource/obbba-harms-people-with-disabilities-limits-on-state-directed-payments/; Natalie Kean & Gelila Selassie, "What's in the Budget Reconciliation Act of 2025 and What Does it Mean for Low-Income Older Adults' Access to Health and Long-Term Care?," Justice in Aging, Aug. 13, 2025. https://justiceinaging.org/budget-reconciliation-and-low-income-older-adults/

[23] Medicaid and CHIP Payment and Access Commission (MACPAC), "Mandatory and Optional Benefits," March 15, 2021. https://www.macpac.gov/subtopic/mandatory-and-optional-benefits/

[24] MACPAC, "State Management of Home- and CommunityBased Services Waiver Waiting Lists," Aug. 2020, www.advancingstates.org/sites/default/files/State-Management-of-Home-and-Community-Based-Services-Waiver-Waiting-Lists.pdf

[25] Jessica Schubel, et. al, "History Repeats? Faced With Medicaid Cuts, States Reduced Support For Older Adults And Disabled People," Health Affairs, April 16, 2025. www.healthaffairs.org/content/forefront/history-repeats-faced-medicaid-cuts-states-reduced-support-older-adults-and-disabled

[26] Ibid.

[27] Ibid.

[28] California Health Care Foundation. " How Could Cuts to Medi-Cal Home and Community-Based Services Impact California?" Oct. 2025. https://www.chcf.org/wp-content/uploads/2025/10/HowCutsMediCalHomeCommunityBasedServicesImpactCA.pdf

[29] Ibid.

settings, experience preventable hospitalizations, and face a decline in overall health and wellbeing.[30]

The lack of adequate and robust investment in the direct care workforce leaves massive barriers to community living and aging in place for people with disabilities and older adults. Direct care workers, one of the fastest growing workforces in the country, are among the most underpaid workers in the country, despite the critical care they provide for older adults and people with disabilities to live and age with dignity.[31] Direct care workers are paid an average of just $26,000 per year and are less likely to receive benefits through their employers.[32] As a result, nearly half of direct care workers rely on public assistance to make ends meet, including the 30 percent of direct care workers enrolled in Medicaid for their own health insurance.[33] The low pay and lack of benefits means that many workers are forced to leave the field, increasing training and turnover costs for employers and diminishing the quality, consistency of, and access to care for family caregivers, older adults, and disabled people.[34] While the rate of people who count on HCBS to work and live has steadily increased, the number of direct care workers has not kept pace with the demand for services.[35] The massive cuts to Medicaid could further suppress wages of direct care workers and will only increase the turnover rates and the likelihood of workers leaving the field.[36] Without a well-compensated, robust workforce, people with disabilities, older adults, and family caregivers will continue to go without life-sustaining care.

An underpaid direct care workforce requires an overreliance on the support of family caregivers who often must take time out of the workforce or leave the paid workforce entirely to provide care if they are unable to find or afford paid help. Family caregivers experience significant financial, physical, and mental hardship.[37] Approximately half of family caregivers experience negative financial impacts because of minimal support and the high costs of care and structural inequities persist based on race for Black and Hispanic family caregivers who face the largest negative financial negative impacts. [38] Family caregivers provide critical supports to people with disabilities and older adults, but remain unsupported and cannot be the only option for people with disabilities and older adults. Approximately 25 percent of older adults with significant long-term care needs do not have a family caregiver or other loved one who provides support for

[30] Jennifer C. D'Souza et. al, "Hard Times: The Effects of Financial Strain on Home Care Services Use and Participant Outcomes in Michigan," The Gerontologist, Mar. 27, 2009. https://academic.oup.com/gerontologist/article-abstract/49/2/154/552362?redirectedFrom=PDF
[31] BLS, "Occupational Outlook Handbook: Most New Jobs," Aug. 28, 2025. https://www.bls.gov/ooh/most-new-jobs.htm
[32] PHI, "Direct Care Workers in the United States: Key Facts 2025," Sept. 15, 2025. https://www.phinational.org/resource/direct-care-workers-in-the-united-states-key-facts-2025/ .
[33] Ibid.
[34] Ibid.
[35] Amanda Kreider & Rachel Werner, 2023, "The Home Care Workforce Has Not Kept Pace with Growth in Home and Community-Based Services," *Health Affairs,* May 2023. https://pmc.ncbi.nlm.nih.gov/articles/PMC10278236/pdf/nihms-1899993.pdf
[36] Veronica Faison and Sarah Javaid, "Medicaid Cuts Threaten the Direct Care Workforce," The National Women's Law Center, April 2025. https://nwlc.org/wp-content/uploads/2025/04/Medicaid-Cuts-Threaten-the-Direct-Care-Workforce.pdf
[37] AARP & National Alliance for Caregiving, "Caregiving in the US: Research Report," Jul. 2025. www.aarp.org/content/dam/aarp/ppi/topics/ltss/family-caregiving/caregiving-in-us-2025.doi.10.26419-2fppi.00373.001.pdf
[38] Ibid.

their care needs, and the number of older adults without family to fill caregiving needs is expected to double by 2080.[39] Diminishing access to HCBS and cutting direct care jobs will create additional barriers for families already struggling to make ends meet.

Without Medicaid HCBS, the egregiously high cost puts aging and disability care out of reach for most families.

Only the wealthiest can actually afford long-term care and only those who qualify for Medicaid can access it through public programs. This leaves the vast majority of people across the U.S. with little recourse other than paying out of pocket. The average cost for nursing home care in a semi-private room is more than $100,000 per year.[40] Aging and disability care in homes and communities that enable aging in place costs between $60,000 and $288,000 annually.[41] Nearly all adults say it would be very difficult or nearly impossible to pay for a year in a nursing home or a year of assistance from a paid nurse or aide due to the high cost of care.[42] Family caregivers already pay an average of $7,200, or 26 percent of their income, out of pocket for caregiving costs.[43] Unpaid caregiving, two-thirds of which is done by women, is worth more than $1 trillion dollars.[44] In short, the cost of aging and disability care is too much for family caregivers, people with disabilities, and older adults to bear due to limited public investment. This enormous cost creates significant barriers to community living and aging in place.

Solutions that enable all people with disabilities and older adults to live and age with dignity in their own homes and communities are available and Congress must act.

Federal investments in health care and the aging and disability care system must be prioritized to enable aging in place and living with dignity in community to all people with disabilities and older adults. We urge the Senate Special Committee on Aging and the 119th Congress to enact the following solutions:

Repeal the Health Provisions in H.R. 1.

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[39] ASPE, 2023, "Future Change in Caregiving Networks: How Family Caregivers and Direct Care Workers Support Older Adults Now and in The Future," Aug. 2, 2023. https://aspe.hhs.gov/sites/default/files/documents/a449863a8c93838d37f78ccf29e9231f/future-change-caregiving-networks.pdf

[40] Priya Chidambaram & Alice Burns, "10 Things About Long-Term Services and Supports (LTSS)," Kaiser Family Foundation, July 8, 2024. www.kff.org/medicaid/issue-brief/10-things-about-long-term-services-and-supports-ltss/

[41] Ibid.

[42] Liz Hamel & Alex Montero, "The Affordability of Long-Term Care and Support Services: Findings from a KFF Survey," Kaiser Family Foundation, Nov. 14, 2023. www.kff.org/health-costs/poll-finding/the-affordability-of-long-term-care-and-support-services/

[43] AARP, "Caregiving Out of Pocket Costs Study," Jun. 2021, www.aarp.org/content/dam/aarp/research/surveys_statistics/ltc/2021/family-caregivers-cost-survey-2021.doi.10.26419-2Fres.00473.001

[44] Jessica Mason & Katherine Gallagher Robbins, "Americans' Unpaid Caregiving is Worth More than $1 Trillion Annually – and Women are Doing Two-Thirds of The Work" National Partnership for Women & Families, Jun 27, 2024. https://nationalpartnership.org/americans-unpaid-caregiving-worth-1-trillion-annually-women-two-thirdswork/

We urge Congress to repeal the entirety of the health provisions in H.R. 1. The budget reconciliation bill will result in states reducing Medicaid home and community-based services that older adults and people with disabilities rely on to live, work, and age with dignity. Families across this country are already struggling to make ends meet and struggling to afford tens or hundreds of thousands of dollars for care. Implementing H.R. 1 will only make accessing community living and aging in place more difficult.

Strengthen and increase access to Medicaid Home and Community-Based Services (HCBS) by meaningfully investing in Medicaid HCBS and making HCBS a mandatory Medicaid benefit.
We urge Congress to increase federal investments in HCBS and ensure sufficient Medicaid funding. Congress must provide adequate funding to raise wages and benefits for direct care workers and expand the workforce, address waiting lists and availability of services, provide support to family caregivers, improve coordination of HCBS with housing, transportation, and employment supports, and provide immediate relief to people who depend on HCBS in order to reduce the extreme costs of aging and disability care and to meet the large unmet need for aging and disability care in homes and communities.[45] Reducing the institutional bias by requiring states to provide HCBS to Medicaid enrollees who need it will save states significant costs, as the average cost to Medicaid for a person receiving institutional services is 2.9 times higher than a person receiving HCBS.[46] This should include expanding access to respite care for people who are not currently enrolled in Medicaid waivers and must include making HCBS a mandatory service for states to provide.

Strengthen Medicare by adding a Home Care Benefit and Bolstering the Home Health Aide Program
While most Americans do not know Medicare doesn't cover long-term care, 88 percent of voters support strengthening Medicare by adding robust long-term care coverage.[47] Research done by Georgetown University and the Brookings Institution outlined the critical need to add a home care benefit for older adults and people with disabilities who are Medicare beneficiaries.[48] This would ensure that disabled people of all ages and older adults can receive the services they need to remain in their homes and communities. A home care benefit under Medicare should follow a person-centered, self-directed, community-first model and should bolster and enforce the current

[45] Community Living Equity Center at the Lurie Institute for Disability Policy, "Who Needs LTSS? [Data dashboard]." 2024. https://heller.brandeis.edu/community-living-policy/clec/who-needs-ltss.html
[46] Caitlin Murray, et. al, "Trends in Users and Expenditures for Home and Community-Based Services as a Share of Total Medicaid LTSS Users and Expenditures, 2022," Mathematica & Center for Medicare & Medicaid Services, Aug. 29, 2024.
https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltss-rebalancing-brief-2022.pdf
[47] Heart and Mind Strategies, "Medicare/Medicaid Long-Term Care Expectations Nationwide," Dec. 1, 2023.
https://caringacross.org/wp-content/uploads/2024/02/CAG-Medicare-Omnibus-Findings-National-12123-Final.pdf; Matthew Cortland, "A Bipartisan Majority of Voters Support Expanding Medicare to Include Coverage for Long-Term, In Home Care Services," Data for Progress, Oct. 8, 2024.
www.dataforprogress.org/blog/2024/10/2/a-bipartisan-majority-of-voters-support-expanding-medicare-to-include-coverage-for-long-term-in-home-care-services
[48] Judith Feder, PhD, & Nicole Jorwic, JD, "Delivering on Medicare's Promise: Providing a Home Care Benefit for People Who Need Long-term Care," Georgetown Law O'Neill Institute," Sept. 27, 2024.
https://oneill.law.georgetown.edu/delivering-on-medicares-promise-providing-a-home-care-benefit-for-people-who-need-long-term-care/; Sherry Glied, et.al, "Commentary: A home care benefit for Medicare," The Brookings Institution, Sept. 20, 2024. https://www.brookings.edu/articles/a-home-care-benefit-for-medicare/

but limited home health benefit. Adding a home care benefit to Medicare would significantly benefit millions of middle class families who currently must pay tens or hundreds of thousands of dollars out of pocket each year for care or spend down their life savings to qualify for Medicaid to pay for long-term care.

Establish a robust aging and disability care program for people not eligible for Medicaid or Medicare and who cannot afford to pay out of pocket.
Strengthening and expanding Medicaid HCBS and creating a robust Medicare home care benefit would make aging and disability care affordable and accessible for millions of people, but would not meet the needs of millions of middle class families who are ineligible for either program and cannot afford to pay tens or hundreds of thousands of dollars out of pocket annually for aging and disability care. Private long-term care insurance is unaffordable, limited in scope, and has high denials of coverage, with some of the most common disqualifiers including advanced age and disability, preventing the very people who need care from becoming insured.[49] We urge Congress to establish an aging and disability care program for people with disabilities and older adults who are ineligible for Medicaid and Medicare and cannot afford to pay out of pocket.

Increase wages and benefits, including health benefits, for direct care workers.
Investment in the direct care workforce will create economic mobility for the families and communities they are part of, in addition to stabilizing the services families, older adults, and people with disabilities need.[50] Congress must pursue policies to increase direct care worker wages and benefits to support the direct care workforce and the people who need care. This must include adequate funding to states and providers to recruit and retain the workforce. We implore Congress to act on this proven solution – investing in the direct care workforce to raise the wages and support workers' rights to organize, the ability to join a union, and strengthen this workforce to increase availability of care for the people who need it most.

Conclusion
There are proven policies and approaches that would make aging in place and community living possible for all older adults and people with disabilities, bolster the direct care workforce that makes community living possible, and support family caregivers who are at their breaking point. The first and most vital step to ensuring aging in place and community living are possible for all people is to immediately repeal H.R. 1 and the $1 trillion cuts to Medicaid, Medicare, and the Affordable Care Act, prioritizing investments in care instead. We thank you for your attention to the importance of aging in place and community living, and we urge you to take action to enable all people to live and age with dignity in the setting of their choice. If you have any questions or

[49] Liz Hamel and Alex Montero, "The Affordability of Long-Term Care and Support Services: Findings from a KFF Survey," Kaiser Family Foundation, Nov. 14, 2023. www.kff.org/health-costs/the-affordability-of-long-term-care-and-support-services/; Jordan Rau and JoNel Aleccia, "Why Long-Term Care Insurance Falls Short for So Many," KFF News, Nov. 22, 2023. https://kffhealthnews.org/news/article/dying-broke-why-long-term-care-insurance-falls-short/; National Council on Aging, "6 Potential Roadblocks to Getting Long-Term Care Insurance," Dec. 9, 2024. www.ncoa.org/article/6-potential-roadblocks-to-getting-long-term-care-insurance/
[50] Christian Weller, Beth Almeida, Marc Cohen, & Robyn Stone, "Making Care Work Pay: How Paying at Least a Living Wage to Direct Care Workers Could Benefit Care Recipients, Workers, and Communities," LeadingAge, Sept. 11, 2020. https://leadingage.org/wp-content/uploads/2022/10/Making-Care-Work-Pay-Report.pdf

would like to discuss further, please contact Tory Cross, Associate Director of Federal Policy & Government Relations at Caring Across Generations, at tory@caringacross.org.

Sincerely,
Tory Cross, Associate Director of Federal Policy & Government Relations
Caring Across Generations

Project Freedom Inc.
Housing That Supports Independence
223 Hutchinson Road, Robbinsville, NJ 08691
Phone: 609-448-2998 / Fax: 609-448-6389 / Web: www.projectfreedom.org

December 3, 2025

Senate Special Committee on Aging
628 Hart Senate Office Building
Washington, DC 20515

Senators:

I'm submitting this letter on behalf of Project Freedom Inc. to tell my personal story. Project Freedom is a 41-year-old nonprofit that provides housing for people with disabilities. I am its co-founder, Associate Executive Director, and tenant with a lifelong severe disability.

Project Freedom manages nearly 800 apartments across six counties in New Jersey, all of them designed for individuals who use wheelchairs. I also live in the original 30-unit apartment complex. I have a severe physical disability, but because it is Cerebral Palsy, I'm categorized as having developmental disability. I'm also a senior citizen. Nevertheless, I identify and represent people with severe physical disabilities, whatever the cause, who want to live independently.

Since moving in 1991, I have seen people with severe physical and developmental disabilities thrive as my neighbors with various levels of support from community-based services. They came from nursing homes and state-operated institutions. As Project Freedom grew from one complex to the current 12, my view expanded as we housed people with various types of disabilities. Again, the level of support services from community-based agencies was the key to people with disabilities living successfully in their communities. I have also seen tenants fail spectacularly because they lacked sufficient support.

Early in Project Freedom's history, we were a Center for Independent Living (CIL) before regulations forced us to choose between the two programs. We chose housing, but the operating philosophy and the advocacy of CILs were imbued in our operations. Today, the tenants with disabilities living in our 12 complexes are supported by four

CILs. We see how vital CILs are for supporting, integrating, and advocating for people with disabilities in the community. We work closely with CILs in terms of advocacy on statewide disability issues and have earned their trust.

Project Freedom's story is also my story. Without home and community-based services, I could not work for Project Freedom. I'm totally dependent on others for my daily care, yet Project Freedom exists and houses others because I have that support. Home and community-based services are vital for maintaining the right of people with disabilities to live, be gainfully employed, and thrive in their communities. These services must be maintained and expanded.

The Olmstead Decision affirmed the rights of people with severe disabilities and Seniors to live in their communities in "the least restrictive environment." For many, exercising that right is not possible without community-based services.

Thank you for the opportunity to submit my story

Respectfully Submitted:

X His Mark

Norman A. Smith
Associate Executive Director

Stories for the Aging Committee:

1) My name is Shyla Patera. I live in Great Falls, Montana . I am a Montanan with disabilities of cerebral palsy and glaucoma from birth. Throughout my adult life, I have used personal assistance services or community first choice services to live , work, and play in my Montana community. I received my Bachelor of Arts from Montana State University. I lived in Philadelphia. I returned to Montana and presently work for North Central I Independent Living as their Policy Coordinator. I love my job. I love being a part of the Great Falls MT community.

   None of this would be possible without the support of Montana Medicaid for Workers with Disabilities. As the Policy Coordinator for North Central. Independent Living Services, Inc., a center for independent living that serves north central Montanans with disabilities, I worry that younger people and myself will not have the support of Medicaid when we most need it. This is an issue because private insurances do not cover home healthcare and HCBS services at the same rate as Medicaid does Medicare coverage is limited on older American act care as well. Although that is the case, I advocate for the passage of the Older Americans Act and all healthcare subsidies that will help all Americans with physical disabilities or mental health mental health issues, and unidentified disabilities as well.

   I want to age in place in my home and I want others to have that same opportunity if they desire that opportunity.

   I am also a daughter of someone who has recently passed from Alzheimer's dementia. My mother was able to live in her home with some community supports from our local Easterseals day program and home healthcare. States used to have the opportunity and availability to try demonstration programs in Medicaid. I fear with the passage of HR 1 that match rates will change and state share and support will increase thereby limiting potential services offered to all of us as Americans with disabilities. Many of us with disabilities also rely on accessible, affordable housing and transportation, supports and affordability.

   Thank you for reading my story and taking action on behalf of Americans with disabilities and seniors. Please advocate for Medicaid and Medicare and fund them to the maximum extent possible. Please protect SNAP and other food programs as well as transportation and housing programs and funding. This will allow Americans with disabilities to live in their communities of choice. - Shyla Patera

   a) I am an attendant for Shyla Patera who has employed me for 17 years. I, myself have a Traumatic Brain Injury which makes this position extremely difficult. Without the financial support provided by Social Security and DPHHS this job

would be impossible. So I do urge you to support this bill. - Mark Sanders Sanders

2) The Partnership is the only U.S. disability-led nonprofit organization with a focused mission on equity for people with disabilities and people with access and functional needs throughout all planning, programs, services, and procedures before, during, and after disasters and emergencies. One hundred percent of our staff and board are disabled. We achieve our mission through disability-led disaster response and community resilience; community engagement, organizing, and leadership development; advocacy and systems change; training, technical assistance, and research; and unwavering support for local disability organizations.

   The Partnership is a convener for local disability organizations, advocates, emergency managers, public health officials, federal, state/territorial and local government agencies, first responders, and allies across the country to address the urgent needs and systemic gaps and barriers people with disabilities encounter before, during, and after disasters and emergencies.

   How Home and Community-Based Services and how Centers for Independent Living Support Aging in Place, Independence, and Community Integration.

   Home and Community-Based Services (HCBS) provide the essential supports that allows people and older adults to live in our own homes and participate fully in communities of their choice. These services include personal assistance with activities like transferring, bathing, dressing, grooming, and toileting, along with cleaning, cooking and meal preparation. Continuity of HCBS throughout disasters is critical for maintaining health, safety, and independence. Without stable access to the workers and the frequent assistance that HCBS provides, disabled people are placed at immediate risk and may be forced into institutional settings during emergencies.

   Centers for Independent Living (CILs) are consumer-led nonprofit federally funded organizations that are required to be led by a majority of disabled people and to advance community living through core services such as peer support, information and referral, independent living skills training, individual and systems advocacy, and assistance with transitioning youth into adulthood and from institutional settings into the community.

   Throughout disasters some CILs also help consumers navigate the accessible, affordable, integrated, housing shortage arena; support with applying for relevant services when applicable; and prepare for disasters and emergencies with strategies for different access needs. Their work ensures that disabled people and older adults can age in place, remain connected to their communities, and avoid institutionalization.

   These programs play a life-saving role during disasters. Individuals who have consistent in-home support can safely evacuate, maintain health and independence during power

outages and disasters, and avoid hospitalization or institutionalization. When there's a gap in HCBS, even briefly, people lose access to critical supports, including personal attendants. We see this daily through our Disability & Disaster Hotline: when HCBS breaks down due to staff shortages, transportation disruptions, or funding gaps, people are pushed into nursing homes or left without assistance during emergencies.

Underfunded CIL services and HCBS are an immediate safety risk during extreme heat, wildfires, hurricanes, floods, tornadoes, and other disasters.

Why These Programs Matter
Sustained, reliable funding for HCBS and CILs is essential for keeping disabled people and older adults safe, independent, and fully participating in their communities. Cuts to Medicaid, or policy changes such as work requirements that jeopardize eligibility, would increase waiting lists and the workforce shortage, and cause widespread loss of the supports people rely on to survive. Without HCBS, many individuals would face forced institutionalization, isolation and neglect, or institutionalization.

For millions of people, HCBS and CILs are not supplemental, they are the infrastructure that makes community living possible. These programs enable people to work, attend school, raise families, participate in community life, and remain safely in their homes through both everyday challenges and large-scale disasters. Strong federal commitment to HCBS and CILs is an investment in autonomy, dignity, economic participation, and public safety.

The risks facing people with disabilities and older adults in emergencies are predictable and preventable. We have the knowledge, the evidence, and the community infrastructure to keep people safe, but HCBS and CILs must be adequately funded and supported to function when they are needed most. When these systems fail, the cost is measured in lives, not in dollars. A strong federal commitment today will prevent catastrophic outcomes and ensure that no one is left behind in the next disaster. - Germán Parodi & Shaylin Sluzalis

3) Dear Senators,

Hello, my name is Thomas Wade, from Milford Connecticut, and I am writing to share how Home and Community-Based Services (HCBS), Centers for Independent Living (CILs), and other services and supports, some of which are primarily funded through Medicaid, positively affect my life. These programs enable me to live, work, thrive and be an active part of my community. As a result of a spinal cord injury, I am paralyzed from the shoulders down, and require assistance for all Activities of Daily Living (ADLs), which include showering, meal prep, driving, and a number of other activities.

I have been the recipient of various programs which would be, and currently are being affected by cuts to Medicaid and direct federal funding. Currently, I am receiving services

through a Center for Independent Living, which includes advocacy and basic information and referral. And, I also receive support with personal care assistance, and ongoing support for the specialized technology I use to get through my daily life.

After receiving a bachelors and masters degree, I interviewed at a number of agencies, however at the time , the only organization which offered me employment was a Center for Independent Living (CIL). Through their understanding of disability, which included peer support, guidance, and work accommodations, I was able to work successfully for approximately two years before taking employment as a Vocational Rehabilitation Counselor with the State of Connecticut. After attending night school and becoming certified as a social studies teacher, I went on to teach at a public high school for 30 years and am now back working at another CIL as an advocate, all of the time living independently, and eventually purchasing my own home.

I was able to accomplish these tasks, along with others such as snow skiing, traveling, swimming, attending social events through a number of different programs. As stated above, the Centers for Independent Living were and are an essential part of my life, the Connecticut Medicaid For Employees With Disabilities (Med-Connect) program has paid for my personal care assistance which are necessary in helping me get through all my different activities of daily living. These of course are only a few of the many programs which are essential for people with disabilities.

These programs truly matter, which is why reliable, consistent funding, as well as your support, is essential for the physical and emotional well-being for people with disabilities. If nothing else, a simple cost-benefit analysis shows that without these programs, people such as myself, have a very realistic chance of ending up in a nursing home, or having to stay home, not work and contribute to society in the many ways we do each and every day.

Thank you for considering my story and learning more about how these services have assisted me in living a satisfying, productive life within my community. I hope you will continue to support these essential programs for all people with disabilities. Feel free to contact me at the street address or email noted below.

Sincerely,
Thomas Wade, MA, MPA
11 Westland Ave., Milford, CT 06460
Email: wade.thomas@sbcglobal.net or tom.wade@indnw.org

4) Statement on the Impact of Home and Community-Based Services

Home and community-based services have not only improved my quality of life—they've given me the freedom to live it fully. These services are the bridge between surviving and thriving. Because of them, I'm able to get out of bed each morning with the support I

need, care for my daughter, and step into the world as an independent woman with purpose and pride.

With access to transportation and daily living assistance, I can do the things many take for granted—like going out to eat, attending school events for my daughter, or simply enjoying a self-care day to protect my mental health. I'm not just present in my community—I'm active in it. I organize events that uplift disability rights, collaborate with advocacy groups, and help interpret the needs and dreams of our community so we can build a better future together.

Without these services, I would be isolated—trapped inside my home, unable to work, travel, or care for my child. But with them, I've become a leader, a mother, a professional, and a voice for change. They've given me the confidence to know that I can do anything I set my mind to—and to show others that they can too.

These services don't just support individuals—they empower movements, families, and futures. I am living proof. - Justina Plowden

5) My name is Julie Falco. I am 60 years old, and I have lived with multiple sclerosis for nearly forty years. At this point in my life, I am mostly bed-bound. Every day, I navigate my disability with the little strength I have and the hope that I can continue to live in my own home — a place filled with memories, comfort, and the sense of self that I fought hard to reclaim.

A few years ago, when I broke my leg, everything changed. I was sent to a nursing home for what I was told would be a short rehab stay. Instead, I became trapped there during the COVID pandemic. Those years are some of the darkest of my life. I watched people I cared about — roommates and friends I made in that time — slowly fade. I saw people languish, lose their spark, and die alone. It was heartbreaking, traumatizing, and it left me with a fear I still carry inside me every day.

Coming home was like being given a second chance at life. But staying here requires help — help that isn't optional, help that isn't fully covered. I rely on CNA-level caregivers and homemakers to bathe me, dress me, prepare meals, and keep me safe. The hours I receive simply don't cover what it takes for me to survive at home. I've had to put essential care on credit cards just to pay for the additional help I need, including a live-in aide. No one should have to go into debt just to remain in the place that gives them dignity.

The truth is, the thought of being forced back into a nursing home feels unbearable. After what I witnessed — after what I lived through — I don't know how I would emotionally or physically withstand going back. For me, this isn't about convenience. It isn't about comfort. It is truly about life and the will to keep living it.

HCBS is the lifeline that keeps me in my home, connected to the world, and able to wake up each morning with a sense of purpose. Without enough hours, people like me are pushed toward institutions where we lose our independence, our community, and too often, our hope.

I am pleading with lawmakers: please protect and expand HCBS. Increase the caregiving hours available. Strengthen the supports that allow people with disabilities to remain in their homes, where we can live — not just exist.

Thank you for hearing my story. For me, and for so many others, this truly is life or death. - Julie Falco

6) [My name is] Judy Weddle. I am with Skill. I really need my service and my medical card because I am disabled. - Judy Weddle

7) If I didn't have the services I do have I would be at the ER more then I should be my sugar drops during the night I have scoliosis and have a lot of health issues my workers make it to wear I'm not in a nursing home being abused and no one come visit me so please make it possible for us to keep our services and medical because I had a kidney transplant and I cant afford my meds without insurance. - Elizabeth Selby

8) My name is Steve Foelsch and I have been a quadriplegic wheelchair user for 40 years. After I wrecked my motorcycle but before I qualified for HCBS I was a 20-year-old man living in the back of my 60-year-old parents' house. My frail, unprepared and untrained parents were also responsible for my daily care such as bathing, bowel programs and lifting me into my wheelchair. My life was going nowhere.

   After I received HCBS I immediately enrolled in community college and then moved into my own apartment at the University of Missouri. HCBS with its Consumer Directed Services taught me personal responsibility and organizational skills by requiring me to be the boss and hire, train and schedule my own Personal Attendants and accept the consequences of not doing a good job. This in turn built the self-confidence, self-agency, and self respect I needed to prepare myself for my future.

   My Personal Attendants came over early in the morning to get me ready for class and came over late at night to get me in bed after studying, well, I think I ate some pizza and drank some beer a night or 2 while at school but nonetheless I earned a BA in history and a M. Ed. I have been employed for 25 years. I have worked as a teacher, a college professor and a Public Policy Advisor.

   HCBS not only increases human dignity it makes good economic sense. HCBS are much less expensive than medical facilities. People with disabilities are not sick! People with disabilities that have HCBS receive the time, services and support they need as well as experience better health outcomes than those with and without disabilities that are institutionalized.

If it were not for HCBS I would be isolated and living a life of quiet desperation inside of a nursing home. With the help of HCBS I am a productive and active member of my community and contribute to my local economy by paying taxes, rent, insurance and groceries. HCBS also helps me to be a good neighbor, teacher, volunteer and active community member. Instead of limiting eligibility to HCBS we should be encouraging people to leave voluntary and involuntary incarceration in medical facilities and live as independently and inexpensively as they can. - Steven Foelsch

9) Dear Senators,

Hello, my name is Alma Silver from West St. Paul, MN, and I am writing to share how Home and Community-Based Services (HCBS), Centers for Independent Living (CILs), and other services and supports positively affect my life. These programs enable me to live, work, and thrive in my community.

Cuts to Medicaid funding will impact disability community members like me. I rely on state-funded Medicaid programs to pay my team of personnel care attendants (PCAs), who help with activities of daily living, so that I can live independently at home. With consistent PCA support, I have maintained meaningful work, traveled around the world, and built a vibrant social life. Medicaid programs prevent people like me from being institutionalized and placed in group homes against our will.

The level of independence that I have achieved because of PCA services may soon be out of reach for so many people in my community. To comply with new federal budget limitations, states are expected to cut funding for home and community-based services (HCBS) and other essential benefits not required by federal law. These services that keep disabled people alive are being deemed unnecessary and disposable. The withdrawal of funding for life-sustaining services is inhumane and unacceptable. People will be institutionalized, and may die directly as a result of any congressional decision to further cut HCBS, CILs, and all other related programs that are funded through Medicaid.

Thank you for considering my story and learning more about how these services help me thrive in my community. I hope you will continue to support these essential programs.

Sincerely,
Alma Silver

10) Dear Senators,

Hello, my name is Vera Bowman, and I live in Chicago, Illinois. I am a 59-year-old disabled woman, turning 60 in February, and I am writing to share how Home and Community-Based Services (HCBS) and other disability supports allow me to live safely and independently in my community.

How These Services Support My Independence
I rely on multiple community-based supports, including housing assistance (Section 8/CHA), community mental-health services, ADA Paratransit transportation through the RTA, and independent-living resources. These are all part of the broader HCBS ecosystem.

These supports help me:
• maintain stable housing as an older adult with disabilities
• manage depression and anxiety with consistent mental-health care
• avoid isolation and stay connected to resources
• handle daily tasks during periods of chronic pain, stress, or limited mobility

Transportation is especially critical for my independence. Through the RTA ADA Paratransit program, I can use subsidized Uber rides, which allow me to travel to medical and essential appointments independently and safely. As someone with depression, social anxiety, and difficulty navigating crowded public spaces, being able to ride alone is not just helpful — it is absolutely necessary for my health.
I also rely on the free disability bus ride card when I cannot afford Uber, ensuring I can still reach my appointments and basic needs.

Without these services, I would miss medical appointments, struggle to obtain essentials, and face far greater isolation.

Impact on Education, Employment, and Community Participation
Because of these supports, I was able to earn a Master of Fine Arts from DePaul University, which would not have been possible without stable housing and disability accommodations.

Today, HCBS-related supports help me:
• pursue remote, flexible employment that fits my health needs
• travel safely to medical and community appointments
• participate in educational, cultural, and community activities
• maintain independence while managing my mental-health conditions

These programs allow me to remain connected to my community rather than becoming isolated or overwhelmed.

Why These Programs Matter
Stable funding for HCBS is essential for people like me. If these services were cut, delayed, or underfunded, the consequences would be severe:
• increased risk of homelessness
• deterioration in mental and physical health
• inability to attend medical appointments
• loss of independence

• social isolation and reduced community participation

I have already experienced what happens when resources are inconsistent or delayed, and those moments put my stability and safety at risk. Reliable funding for HCBS protects older disabled adults like me and allows us to live with dignity in our own homes.

Thank you for taking the time to hear my story and understand how critical these programs are to the wellbeing and independence of disabled individuals and older adults across the country. I ask that you continue to strengthen and protect HCBS and related supports.

Sincerely,
Vera Bowman

11) Dear Senators,
I am a sixty-two year old person with autism and other challenges and I receive services from the Autism Waiver to help me get out into my community. I am mostly homebound, and I have never driven a car or used a credit card, and I have very little resources to help with daily living, getting essential needs met, and I depend on my support person to help with these things, to get out in my community, and to improve my quality of life. They (along with a mental health caseworker) also help me get medical services I need, which I now require more of as I am aging. There are so few services for older people who have autism! But lately, I am so scared that I will lose the assistance I have, as well as other government supports including housing assistance. I fear my life would end if I were to lose the services I have.

I am asking that you please protect the disabled people in this country who rely on these services to live. I am not a disposable person, as some might think. Over my life, I have contributed to society in many ways, just not the usual ways. It is a mistake to think that people with autism do not care about others and the world around them. I have a very strong moral center, and I have helped others even with the many limitations I have. Please have the same moral duty to help people with disabilities, because it is all of our duties to do so, but especially those with the power that you have. In the future, it is how our society will be judged: by how we treat all citizens of this country, including disabled and low income citizens.

Thank you for reading my message, and please continue to fund the vitally important programs that allow us not to live, and not just to barely survive, because without them, we will not survive, let alone thrive. I am exhausted from living in fear every day, every year, of losing the little I have. If you could only imagine what that is like. Also, what we have to do to maintain services is harder sometimes than living with the challenges of having a differently-abled brain. I want to live what is left of my life in peace and security, just like every other American. Thank you again for reading this, and I wish all of you a

happy holiday season.

Sincerely,
Beth Greenspan

12) Dear Senators,

Hello, my name is Julia Simko from West Windsor, New Jersey, and I am writing to share how Home and Community-Based Services (HCBS), Centers for Independent Living (CILs), and other services and supports positively affect my life. These programs enable me to live, work, and thrive in my community.

How These Services Support My Independence
I receive rideshare transportation support and I possibly get my housing voucher through HCBS. I'm hoping to go through a program that helps people with disabilities complete the written test for getting the Learner's Permit for driving and complete a Mental Health First Aid certification course through the CIL in the county I live in. (The program for testing for a Learner's Permit is held through a partnership with the Division of Vocational Rehabilitation (DVR)). The rideshare helps me live independently because I use it to get to church services and activities, college classes and activities, and the polls to be a board worker come election time, to name a few places and situations. My voucher keeps me off the streets.

Impact on Education, Employment, and Community Participation
The rideshare support helps because I can't learn virtually. My brain just doesn't work that way and the kind of activities I do at school just don't translate online, especially with a budget like mine. My church services and some church activities are hybrid and one is virtual, but technology fails sometimes and I find it more rewarding to be there in person. I have zero interest in the nature of the virtual activity.

Why These Programs Matter
Stable, reliable funding for HCBS, CILs, and related supports is crucial because it helps me and so many others to survive and thrive. If these supports are cut, The New Jersey government and all the other 49 state governments will be forced to cut our support. Frankly, I believe you should be giving us even more than you are. It's almost impossible to find a doctor who isn't linked to a hospital or medical center, you offer zero support for those of us who rely on HCBS and want to become or are parents, you're still arguing about asset limits and the marriage penalty, and HCBS is optional! What you're doing now feels diabolical. Progression, not regression.

Thank you for considering my story and learning more about how these services help me thrive in my community. I hope you will continue to support these essential programs.

Sincerely,

Julia Simko

13) My Home Health was canceled without prior notice, no time to plan! My care is life or death! I was able to get it restored but something's very wrong! - Bart Brophy

14) As someone who is late to the physical disability life I have depended on Centers for Independent Living to help me obtain freedom with an adaptable wheelchair and access to assistive technology that allows for more independent living in my community. I have also become one of their employees. I see the impact that CILs have on the disabled communities lives because I work in the field and I utilize their services, not only for myself but for my grandchildren as well. These are vital services for the disabled and aging community and they need to be maintained but it would help so many more people if the budget wasn't only maintained but increased. The need is great and the value far outweighs the need. Thank you. - Jessica Warrick

15) Thanks for this opportunity to share my story as a senior about to turn 80 years old. I have been working in senior services for over 25 years with hands on as a caregiver for my husband until his death over 20 years ago. Now, as a Service Information and referral specialist I can speak from experience, that planning and prioritizing your life journey is the best life to live.

    I am in good health a 20-year breast cancer survivor, arthritis in my right knee, but I am in good health, because I try very hard to take care of myself. I do have devoted daughter whom I share a home with, and she is my care partner.

    A care partner is someone who works alongside sharing information that is vital to living well and honest about every communication. This person must be willing to be honest about what is needed to partner with someone who is aging.

    Believe me, it's not gonna be easy for the aging person not the care partner. Situations can change and you have to pivot sometimes. But the most important item is to be truthful as to what you will or will not do.

    I hope my story will shine a light on the aging community to pay close attention to self - take time for you and strengthen the areas in which you need to make changes. Do it today, do not procrastinate!!! This story is short and to the point, however, it's not over. Thanks for the opportunity and let me help this aging community stay alive and well. - Gloria Gaddy

16) My disability started at age 57. I am now 64. HBCS is needed as American are aging gracefully and living longer due to medical miracles with health care and advances with prescriptions to increase life expectancy. However, disabled individuals and senior citizens prefer living within their own home with assistance with help that we unable to do alone without hurting ourselves or falling. Also, arthritis with seniors limits a lot of our movements. In addition assistance living are so expensive and hard to find with good

help and care 24 hours is a very difficult. In addition some horrible things that happens to our love ones. - Alfreda Walls

17) Updated Statement for the U.S. Senate Special Committee on Aging
Hearing: The Importance of Community Living for Older Adults and Disabled People
Date: December 3, 2025
Submitted by: Kristina Herrin Starling, Lakeland, Florida

Chairman, Ranking Member, and Members of the Committee:

Thank you for the opportunity to share my story and speak about the life-changing impact of Home and Community-Based Services (HCBS). My name is Kristina Herrin Starling, and I am a disabled adult living in Lakeland, Florida. I live with Secondary Progressive Multiple Sclerosis (SPMS), and I am now wheelchair-bound with severely limited mobility. HCBS is the only reason I am still able to live in my home and participate in my community.

My condition has progressed significantly in the past few years. I experience muscle weakness, sensory loss, and severe balance problems. I fall multiple times each month, and each fall increases the risk that I will suffer a serious injury that could force me to leave my home and be placed in a nursing facility. Without proper in-home support, that is not just a fear—it is an eventual certainty.

What has prevented that outcome so far are the extraordinary sacrifices made by my caregivers. My son, Nicholas, quit his job and moved from Kentucky to Florida last year because I was not receiving enough Medicaid-funded hours to keep me safe. Since then, he has taken on the responsibility of my daily care, often around the clock. To help us survive financially on my $1,399 per month in Social Security Disability, he even sells his plasma every month to subsidize our basic needs. No adult child should have to harm their own health to keep their disabled parent out of a nursing home simply because HCBS hours are inadequate.

My paid caregiver, Kaylee, also plays an essential role—assisting with mobility, bathing, toileting, household tasks, and monitoring me closely to prevent injury. But without enough authorized HCBS hours, she cannot be here as often as my safety requires. The remaining hours fall on my son, leading to burnout, financial instability, and immense pressure on our household.

The reality is that my HCBS hours are not sufficient to meet the level of care I need to remain safely at home. My son's sacrifices, and the physical and emotional toll on my caregivers, are simply not sustainable. Without expanded support, I will eventually face institutionalization—not because I want to, but because the system leaves me no viable alternative.

HCBS programs were designed to prevent exactly this. They keep disabled people in their homes, save the government money by reducing nursing home placements, and support family caregivers so they do not fall into poverty or medical crisis. Strengthening HCBS is not only fiscally responsible—it is morally necessary.

I urge the Committee to expand HCBS funding, increase authorized care hours, improve caregiver wages, and support family caregivers who sacrifice their livelihoods to keep loved ones safe at home. Decisions made here will determine whether people like me can continue to live in our communities with dignity, stability, and safety.

Thank you for listening to my story and for your commitment to improving the lives of disabled Americans. - Kristina Herrin Blanchard

18) Dear Senators: My name is Martin. I am a 68 year old disabled man retired from 45 years of running my own business (actually 2 of them!) I would Not have been able to do so without the help of my local support network known as an Independent Living Center that provided me with support. This Center funded in part (almost wholly) by Medicaid provides Personal Care Attendant (PCA)services advise (how to set up and implement so I can get back to work). PCA services allowed me the freedom and the structure to be able to productively work and pay my taxes just like any able bodied citizen. I as so motivated to get back to work after a devastating spinal cord injury that I actually ran 2 businesses...my family campground business, Westport Camping Grounds, and my own mobile DJ business, MC Music Productions. MassHealth funding for these essential services that help the disabled become independent and productive individuals are being systematically threatened and dismantled all in the name of "fiscal responsibility." But in the long run, eliminating crucial Medicaid funding for Independent Living Centers will, in effect, physically, emotionally, and socially hurt me and other disabled citizens of Massachusetts. Please, please do not cut Medicaid funding for these programs. - Martin Costa

19) We are unable to find any community living opportunity for our daughter. Medical complexity is sited yet as parents we were provided with only minutes of training to manage her cares. Iowa provides no caregiver stipend which could be a viable alternative over a placement. May have to look at out of state placement. - Kevin Harris

20) My name is Kim Brock, and I'm a mom of two, a homeschool educator, a disability advocate, and someone who believes deeply in Inclusive Wellness—active lifestyles for all. I also happen to have severe cerebral palsy. With the right supports, I live a full, active life: riding my adaptive bike ten miles at a time, walking laps with my walker, swimming, staying busy with my kids, and speaking to students about inclusion and resilience.

None of this would be possible without strong Home and Community-Based Services.

When I was younger, I learned early what it meant to go without support. My family made things work because we had no choice—but every task took longer, every step came with fear of injury, and my independence was often limited not by my disability, but by systems that weren't built with people like me in mind.

As an adult, those gaps became even clearer. Before I owned my home, I struggled to find accessible rentals. Most landlords wouldn't allow modifications—simple things like grab bars, ramps, or widened doorways. Without HCBS-funded supports, I wouldn't have been able to remain safe and active in my community while searching for stable housing. And today, even in my own home, HCBS services—like personal attendant care, respite, and access to needed equipment—are what allow me to parent my daughters, manage my household, and maintain my health.

Strong HCBS funding doesn't just help me survive—it allows me to contribute. I'm able to teach my children, model inclusion through my lifestyle, stay active in my community, and speak to students about overcoming circumstances and embracing differences. HCBS is the bridge that turns possibility into participation.

Without adequate funding, people with disabilities are often left with two choices: go without essential care or be forced into institutions far from their families and communities. Neither should ever be acceptable in a country that claims to value independence and dignity.

I am living proof of what happens when HCBS works. My children get to grow up with a mom who is present, engaged, and active. My community gains a leader and advocate. And I get to live a life defined not by limitation, but by opportunity.

Strong HCBS funding doesn't just change lives—it lets us live them. - Kim Brock

21) Dear Senators,

My name is Pamela Hoye. I am a disabled senior citizen living in San Diego, California, and disabled from birth from cerebral palsy in 1949. While the effects of cerebral palsy had been severe enough that I needed assistance from personal care providers available to me from our state's In-Home Supportive Services (IHSS), I was able to manage on my own for long periods each day, once I was up, dressed, and in my chair, and with my environment set up for me to access what I needed.

Everything changed in 2009 when cervical stenosis resulted in a spinal cord injury. Thankfully, my respiratory system escaped damage and I could still type with a mouth stick, but I now needed the help of others for completing all my needs and activities, from getting up each morning through going to the bathroom in the night. My county social worker put my name on the waiting list for a Home and Community-Based Services (HCBS) Waiver, which would provide additional personal care assistance.

Since coming to San Diego in the late '70s, following graduation from college, I have served on a number of County Advisory Committees related to Medicaid health programs and to services for senior and disabled residents. Additionally I have served on the boards of directors for two nonprofit organizations, one being a Center for Independent Living (CIL). As you perhaps know, CILs are consumer-run centers offering independent living resources, advocacy, and services for people with disabilities. Since my first paid part-time job as feature writer for a disability focused magazine I have continued as a freelance writer and editor in paid and volunteer capacities; primarily in spiritual themed publications. For fun and leisure, I enjoy reading, British mystery shows, free concerts, watching plants growing in my yard, being walked around the neighborhood, and exercising in a shallow warm-water pool. All of these achievements and activities have been possible with various levels of help from my personal care assistants.

Although sometimes an unfortunate necessity, care facilities for low income individuals are costly to maintain and provide a much reduced level of personal care and support. I have seen the deadening effect of basic institutionalized living on friends who found themselves bound by restrictive, universally applied rules and cut off from their former lives.

This happens when an adaptable range of support services are not available to enable someone to remain in his or her home. The needed support may be as simple as providing grocery shopping and meal prep, ranging up the scale to include a combination of need levels in relation to helping with or performing household tasks (such as cooking cleaning, laundry); personal daily living needs (bathing, dressing, feeding, hygiene, medical procedures one would do for oneself or can be done in the home, etc.); providing transportation; helping with exercise and mobility, to name a few common assistance needs..

Following spinal injury in 2009, I was bracing myself for a necessary move into a longterm care facility. There was uncertainty as I waited for my turn on the HCBS waiting list. Yet, since it is nearly impossible to reestablish independence after an extended period in a longterm care facility, I was determine to avoid this as long as possible…managing to stay in my home with IHSS services, the kindness of a caregiver who worked extra hours without pay, and occasional help from friends. (Not everyone is as fortunate to have such additional support.) Five years later my future was again stabilized. The combined personal care assistance from both IHSS and HCBS programs allowed me to continue the life I had built by enabling remain in my home and maintain ties with friends and community.

Now, at 76, I am thankful to be living a full life and that the needed support was not only available, but able to adapt to my changing needs.

Thank you for your interest in learning how these services help low income seniors and persons with disabilities contribute to and thrive in our communities. Please continue to support these essential programs.

Sincerely,
Pamela Hoye

Make today a breakthrough.

Written Statement for the Record

Maynard Friesz, Vice President of Policy and Advocacy, Cure SMA

U.S. Senate Special Committee on Aging Hearing on

Importance of Medicaid Home and Community-Based Services

Chairman Scott, Ranking Member Gillibrand, and Members of the Committee,

Thank you for holding a hearing on Aging in Place and the impact of Medicaid home and community-based services (HCBS) and other public programs that promote independence and community living for older adults and people with disabilities. Cure SMA, which represents children and adults with a neuromuscular disease known as spinal muscular atrophy (SMA), will focus its comments on Medicaid-funded caregiving services given their importance to individuals with SMA and their families during the holidays and throughout the year. In short, Medicaid caregiving is indispensable to people with SMA. Policy changes or funding cuts that limit access to caregiving services or reduce available hours will lead directly to isolation, increased health risks, and unnecessary institutionalization.

SMA Community Depends on Medicaid Caregiving Services

Most individuals with SMA rely on daily support from Medicaid-funded caregivers to maintain their health, independence, and ability to live in the community.[i] Due to muscle weakness and motor function loss caused by SMA, individuals with SMA often require assistance with wheelchair transfers, grooming, bathroom use, and meal preparation and feeding.[ii] One **adult with SMA** said, *"I am 100% dependent. Without home caregivers I would have to leave my home to live at a nursing facility.* Another **individual with SMA** said, *"Medicaid empowers me to be a contributing member of the community, and without it I would surely be in an institutional setting."*

Access to Medicaid-funded caregiving enables individuals with SMA to attend school, go to work, and engage fully in community life. As another **adult with SMA** shared, *"My caregivers are my lifeline. Without them, I wouldn't be able to be a part of the community or be independent in any capacity."* A **SMA community member** added, *"I am fortunate to have found a reliable, long-term caregiver. Although I am physically dependent, I am cognitively able and fully participate in town and church activities."*

SMA Community Concern About Caregiving Cuts and Changes

Individuals and families affected by SMA frequently struggle to obtain the caregiving hours they require. Many receive far fewer hours than they need, delaying independent living plans or restricting community participation. A **young adult with SMA** noted, *"I receive 48 hours of Medicaid caregiving a week. I need almost 24/7 care to live independently. As a result, I live with my parents who provide many unpaid caregiving hours."*

Limited hours also force individuals to forgo meaningful activities. One **adult with SMA** shared, *"There are lots of things in the community that I would like to participate in, but I can't*

because I just don't have enough hours, and I cannot do them alone due to my SMA."

Individuals and families with SMA are deeply concerned about how Medicaid changes or funding cuts could affect their daily lives. A **mother of two children with SMA** said, *"I worry they'll lose the hours they have, which is barely enough to get them out of bed each day, in bed each night, showered a few times each week, and cover the basic g-tube feeding times."* A **woman with SMA** who works full-time said, *"I worry I will lose caregiving coverage, which could jeopardize my employment if I am unable to get up and ready to go to work each day."* Another **young adult with SMA** added, *"I worry that potential cuts to Medicaid will impact my health and ability to live independently."*

Some individuals with SMA are already experiencing proposed cuts. One **adult with SMA** described how her state plans to reduce her caregiving hours, including the specialized support she needs for safe transfers in and out of her wheelchair. *"If this goes through, the cut would leave me isolated at home and could endanger my health, as I would be forced to limit my food and liquid intake to unhealthy levels due to bathroom limitations,"* she said. *"This ordeal has been overwhelming. It makes me want to scream or cry."* Another **SMA community member** echoed that sentiment by saying, *"The uncertainty to my lifeline is anxiety-inducing."*

SMA Community Priorities for Strengthening Medicaid Caregiving

Cure SMA recently documented caregiving challenges in our *Stuck Inside* national caregiving report.[iii] In addition to limited and threatened caregiving hours, the SMA community identified:

- Difficulty in finding caregivers, driven largely by low wages,
- Restrictive income and asset limits that penalize those pursuing work or financial stability, and
- Lack of Medicaid portability for individuals who move across state lines.

On the caregiver shortage, a **father of a child with SMA** said less than half of his daughter's approved private duty nursing hours are filled in any given week. The family has been *"effectively trapped at home,"* missing family gatherings, vacations, and local events due to nursing support gaps. *"We can't find qualified nurses willing to staff the shifts. The nursing shortage has been the single most important pain point in managing SMA and our daughter's care. It's super frustrating."*

Conclusion

Medicaid-funded caregivers and caregiving services are essential for education, critical for employment, crucial for independent living, and vital for community participation of people with SMA.[iv] Yet individuals with SMA and their families face significant barriers to accessing these services during the holidays and throughout the year.

One **adult with SMA** shared, *"My life-threatening medical condition is actually not the worst thing I have to face. The thing that has most inhibited my quality of life is the constant fight I have to go through daily, just to be able to live in the community like everyone else. With constant threats to Medicaid funding, and the amount of work and advocacy it takes to obtain Medicaid services, it feels like I am constantly being punished for my disability. I am exhausted."* Another **individual with SMA** added, *"Caregiving is not a luxury. It gives people*

the opportunity like me to pursue the same goals as anyone else. The importance of caregiving cannot be understated."

Cure SMA urges Congress to use its oversight and authorizing authority to strengthen Medicaid and ensure that individuals with SMA, and others with complex disabilities, can access the Medicaid-funded caregiving services they need to remain healthy, live independently, and contribute to their communities. Thank you for considering the perspective of Cure SMA and SMA community.

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[i] Cure SMA 2024 State of SMA Report, https://www.curesma.org/wp-content/uploads/2025/04/State-of-SMA-Report2024_vWeb.pdf#page=32
[ii] Cure SMA 2024 National Caregiving Report, https://www.curesma.org/wp-content/uploads/2024/01/Advocacy_Report_Stuck_Inside_vFnl_Web.pdf
[iii] Cure SMA 2024 National Caregiving Report, https://www.curesma.org/wp-content/uploads/2024/01/Advocacy_Report_Stuck_Inside_vFnl_Web.pdf#page=14
[iv] Cure SMA 2024 National Caregiving Report, https://www.curesma.org/wp-content/uploads/2024/01/Advocacy_Report_Stuck_Inside_vFnl_Web.pdf#page=7

Statement for the Record

Submitted to the U.S. Senate Special Committee on Aging

Hearing on the Importance of Community Living for Older Adults and People with Disabilities

December 8, 2025

Ariel A. Simms, Esq.

President and Chief Executive Officer

Disability Belongs™

Introduction

Chairman Scott, Ranking Member Gillibrand, and Members of the Committee, thank you for the opportunity to submit this testimony for the record and for your commitment to advancing the freedom of older adults and people with disabilities to live, work, and participate fully in their communities.

My name is Ariel Simms, and I serve as President and Chief Executive Officer of Disability Belongs™, a diverse, disability-led nonprofit that works to create systemic change in how society views and values people with disabilities. Our mission is to drive cultural and policy change to ensure our full representation and influence, creating a more accessible, equitable, and inclusive society.

For more than a decade, Disability Belongs™ has advocated at the federal and state levels to strengthen community living, economic security, and self-determination for people with disabilities and older adults. Community

living is not only a civil right—it is essential to well-being, longevity, and full participation in American life.

The Importance of Community Living

I am testifying today to underscore the indispensable role of Home and Community-Based Services (HCBS) and the Centers for Independent Living (CILS) in upholding the civil rights of community living for people with disabilities and older adults. The ability to live in one's own home and participate in community life is central to the dignity, independence, and civil rights of everyone, especially for people with disabilities and older adults. HCBS and CILS form the core infrastructure that makes this possible.

Research is unequivocal: community-based supports improve health outcomes, increase economic participation, strengthen autonomy, and reflect what people overwhelmingly prefer.[1]

HCBS, authorized under Medicaid authorities including Section 1915(c) waivers, provide critical services, such as personal care assistance, supported employment, habilitation services, respite, and more, that allow individuals to live independently instead of in institutional settings.[2] These services are the most effective and practical alternative to institutionalization, consistent with the **integration mandate** of the Americans with Disabilities Act (ADA)[3] and the Supreme Court's landmark decision in ***Olmstead v. L.C.***[4], which affirmed the right for individuals with

[1] Cyr, M. (2013). Use of community-based participatory research in primary care. *Journal of Comparative Effectiveness Research*, *2*(4), 405–419. https://doi.org/10.2217/cer.13.45
[2] **Centers for Medicare & Medicaid Services.** (n.d.). *Home & Community-Based Services 1915(c).* Medicaid.gov. https://www.medicaid.gov/medicaid/home-community-based-services/home-community-based-services-authorities/home-community-based-services-1915c
[3] U.S. Department of Justice. (n.d.). *Community integration.* Retrieved November 21, 2025, from https://www.ada.gov/topics/community-integration/
[4] *Olmstead v. L.C., 527 U.S. 581 (1999)* https://supreme.justia.com/cases/federal/us/527/581/

disabilities to receive services in the most integrated setting appropriate to our needs.[5]

At the same time, **Centers for Independent Living**, established under **Title VII of the Rehabilitation Act**, provide peer-driven supports, such as skills training, advocacy, information and referral, and transition services.[6] CILS embody the disability community's long-standing principles of self-direction, choice, and autonomy. HCBS and CILS form the essential infrastructure of community living and independence for people with disabilities and the aging community.

The Growing Crisis: Chronic Underfunding and Direct Support Workforce Instability

Despite their proven value, community living services are in crisis due to persistent underfunding and the ongoing collapse of the Direct Support Professional (DSP) workforce.

DSPs—who provide daily support such as bathing, dressing, transportation, meal preparation, and assistance that makes employment possible—are paid wages far below the value and skill of their work. The result is a national workforce shortage and **annual turnover rates above 40 percent**, driven by inadequate wages and benefits.[7]

For older adults and people with disabilities, the consequences are severe:

[5] U.S. Department of Justice. (2013). *About Olmstead*. ADA.gov. https://archive.ada.gov/olmstead/olmstead_about.htm
[6] Administration for Community Living. (2025, September 17). *Centers for independent living*. https://acl.gov/programs/aging-and-disability-networks/centers-independent-living
[7] National Core Indicators Intellectual and Developmental Disabilities. (2024). *State of the workforce: 2023 survey results: At a glance*. National Core Indicators Intellectual and Developmental Disabilities. https://idd.nationalcoreindicators.org/wp-content/uploads/2025/01/SotW-2023-At-a-Glance-3.pdf

- **Long waiting lists**: Since 2016, more than **500,000 people** have remained on HCBS waiting or interest lists each year; by 2025, this number exceeded **600,000.**[8]
- **Forced institutionalization:** When HCBS is unavailable, individuals are pushed into far more expensive institutional settings—contrary to their wishes and civil rights.
- **Family caregiver strain:** Unpaid caregiving labor now exceeds $600 billion annually, a burden that is growing as services remain inaccessible.[9]

The promise of *Olmstead* remains unrealized for too many Americans.

Policy Recommendations

To stabilize and strengthen community living nationwide, Disability Belongs™ urges the Committee to champion the following policy actions:

1. Permanently Expand and Protect Federal Funding for HCBS

Congress should pursue legislation that enhances the federal Medicaid match (FMAP) for HCBS, encourages states to eliminate waiting lists, and supports building a strong, well-compensated DSP workforce. Disability Belongs™ also urges Congress to make HCBS a mandatory Medicaid

[8] **Burns, A., Wolk, A., & O'Malley Watts, M.** (2025, November 20). *A look at waiting lists for Medicaid home- and community-based services from 2016 to 2025*. KFF. https://www.kff.org/medicaid/a-look-at-waiting-lists-for-medicaid-home-and-community-based-services-from-2016-to-2025/

[9] Otsuka America Pharmaceutical, Inc. (2024, October 24). *New report reveals U.S. family caregivers perform equivalent of a staggering $873.5 billion worth of labor, would surpass revenue of top global companies*. https://www.otsuka-us.com/news/new-report-reveals-us-family-caregivers-perform-equivalent-staggering-8735-billion-worth-labor

service rather than an optional one, ensuring that access to community-based supports does not vary by state.

A permanent HCBS funding mechanism would provide states with the long-term certainty needed to:

- Reduce waiting lists
- Address workforce shortages
- Increase provider rates
- Modernize service delivery
- Expand access to employment-related supports

2. Increase Federal Appropriations for the Independent Living Program

Congress should significantly expand funding for CILS under the Administration for Community Living, recognizing their growing role in community transition, aging-in-place, and disability-led peer support. It is also essential to maintain the Administration for Community Living (ACL) as a unified, fully funded federal agency; recent proposals to defund or redistribute ACL's functions would undermine the nation's independent living infrastructure and weaken disability-led systems of support.

CILS remain one of the few federally funded programs that are designed, governed, and led by people with disabilities themselves. Sustained investment is essential for them to meet rising demand.

Conclusion

Thank you, Chairman Scott, Ranking Member Gillibrand, and Members of the Committee, for your leadership in protecting and strengthening the right of every person to live in the community.

Investing in HCBS and CILS is both a civil rights imperative and a smart fiscal strategy. These programs reflect our country's values, independence, dignity, equity, and full inclusion. Your commitment to advancing community living ensures that millions of people with disabilities and older adults can lead self-directed lives in the places they call home.

Action@DisabilityBelongs.org | (202) 517-6272
www.DisabilityBelongs.org

Statement of Easterseals

for the

United States Senate Special Committee on Aging

Aging in Place: The Impact of Community during the Holidays

December 3, 2025

On behalf of the millions of people with disabilities served through 70 Affiliates in 48 states, Easterseals appreciates the opportunity to submit this statement for the record to the Senate Special Committee on Aging hearing "Aging in Place: The Impact of Community during the Holidays."

The Holidays are a good time to reflect that Home and Community-Based Services (HCBS) through Medicaid are a success for 4.5 million Americans[1] and their families. It lets people with disabilities remain at home and in the community; work; and be engaged, contributing members of society. The right of people with disabilities to live in the community has been reaffirmed through the Americans with Disabilities Act, the Olmstead decision, and more. Much of this progress is at risk of backsliding today.

From a policy perspective, HCBS continues to be a win-win, preserving people's rights and producing significant fiscal savings for taxpayers. It costs Medicaid $36,275 per

[1] https://www.kff.org/medicaid/what-is-medicaid-home-care-hcbs/

person to provide HCBS.[2] In comparison, it can cost almost $400,000 a year for someone with a developmental disability to be in an institution in parts of the country.[3] HCBS through Medicaid is also an important economic driver, supporting 2.4 million jobs.[4] Every $1 the federal government spends on HCBS generates $1.17 in economic activity.[5] HCBS also lets Easterseals participants like Zach in Indiana get a job preparing electronics for repair. HCBS also allows family members to stay in the workforce. Katie in Hawaii was able to keep her career as a financial advisor at a major bank because her son Bennett attends an Easterseals day program. This is the difference between thriving and poverty for millions of Americans.

Today, the public-private partnership between Easterseals and the government is under strain. Easterseals already fills in the gaps when HCBS through Medicaid falls short of the cost of care. The cost of wages, transportation, and rent has all gone up, but Medicaid reimbursement has lagged. In Florida, respite programs for caregivers do not authorize enough hours for a full workday. This means Easterseals Affiliates must absorb uncompensated costs to give family caregivers a day off.

Unintended consequences of forthcoming reductions in federal Medicaid spending mean that HCBS is under threat. HCBS is an “optional” service, meaning it is the first program states look to cut as they receive less federal funding. These cuts are already

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[2] https://www.kff.org/medicaid/how-many-people-use-medicaid-long-term-services-and-supports-and-how-much-does-medicaid-spend-on-those-people/
[3] https://coloradosun.com/2025/11/06/developmental-disabilities-medicaid-cuts/
[4] State Efforts to Address Medicaid Home- and Community-Based Services Workforce Shortages
[5] MoodyAnalyticsmacroeconomic-impact-of-HCBS_expansion_09202021.pdf

starting in places like Colorado, where paid family caregivers will receive 10% less next year.[6] Providers will not even get a modest rate adjustment, resulting in reimbursement falling even further behind the cost of care.[7] This is counterproductive for our shared constituents and for our country's fiscal reality. A recent study showed that a 10% cut to HCBS in California would cost the state over $200 million more a year due to increased institutionalization.[8]

We have come too far to go back. Delores, who is 95 and lives in Easterseals supportive housing in Indiana, was taken out of school during the Great Depression because other children bullied her for her disability. We no longer live in times where children are forced out of school or into institutions. Everyone should have the opportunity that Delores does today to be surrounded by family during holidays and to play with her cat "Beans."

We are grateful for the robust bipartisan support on this Committee for HCBS. We must work together to strengthen HCBS. This can be done by asking the Centers for Medicare and Medicaid Services (CMS) to instruct states to preserve HCBS through a State Medicaid Director Letter.

We must also ensure that the Medicaid provisions of Public Law 119-21 are implemented as intended. This means correctly exempting people with disabilities and caregivers from the forthcoming community engagement requirements. A broad definition

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[6] https://coloradosun.com/2025/11/06/developmental-disabilities-medicaid-cuts/
[7] https://www.jdsupra.com/legalnews/colorado-budget-cuts-hit-home-for-7397351/
[8] https://www.chcf.org/resource/cuts-medi-cal-home-community-based-services-impact-california/

of medical frailty, permitting self-attestation paired with data matching, exempting people through ex parte verification, and reducing administrative burden are among the tools we should use to limit negative consequences.

Easterseals participants already face barriers every day. Lauren in Maryland does not have a salon in her area that can fit her wheelchair. Lauren is breaking down these barriers by seeking to open her own accessible salon. We do not need to create more barriers by making it harder for her to have healthcare and the supports she needs to thrive.

It's particularly appropriate that this hearing is being held on the International Day of Persons with Disabilities. Let's continue to ensure Americans can achieve their goals and live freely and safely in their communities. During a time of year when so many people face isolation, HCBS shows that a better way is possible. We thank the Committee for holding this hearing.

EPILEPSY FOUNDATION

December 8, 2025

The Honorable Rick Scott
Chairman
Special Committee on Aging
U.S. Senate
Washington, DC 20510

The Honorable Kirsten Gillibrand
Ranking Member
Special Committee on Aging
U.S. Senate
Washington, DC 20510

Dear Chairman Scott and Ranking Member Gillibrand:

On behalf of the Epilepsy Foundation of America (EFA), thank you to the Senate Special Committee on Aging for holding a hearing on the importance of community living for older adults and people with disabilities. Medicaid Home- and Community-Based Services (HCBS) are critically important for many people with and families affected by epilepsy, and we appreciate your leadership on this important issue.

EFA is a national nonprofit organization dedicated to improving the lives of people affected by epilepsy through education, advocacy, research, and connection. For more than 50 years, the Foundation has led efforts to raise awareness, reduce stigma, and advocate for policies that make a meaningful difference for individuals living with epilepsy. We also fund cutting-edge research and support early-career investigators working to discover new treatments and therapies. Through our nationwide network of local offices and community partners, the Foundation expands access to care, provides seizure recognition and first aid training, and delivers direct services to those in need.

Epilepsy is one of the most common neurological disorders in the world, affecting people of all ages, races, and backgrounds. Nearly 3.4 million Americans live with active epilepsy, including 456,000 children and teenagers.[1] The condition is defined by

[1] Kobau R., Luncheon C., Greenlund, KJ. About 1.5 million community-dwelling US adults with active epilepsy reported uncontrolled seizures in the past 12 months, and seizure control varied by annual family income-National Health Interview Survey, United States 2021 and 2022. Epilepsy Behav.2024



a tendency to experience seizures-sudden, abnormal bursts of electrical activity in the brain that can disrupt behavior, awareness, and bodily control. Beyond seizures, epilepsy can also lead to challenges such as fatigue, memory difficulties, mood changes, anxiety, and trouble concentrating, all of which can significantly impact daily life. There are multiple types of seizures, and they can look different in different people. Epilepsy is a spectrum disease comprised of many diagnoses, including a growing number of rare epilepsies that are increasingly being identified through their genetic links. Thirty to forty percent of people with epilepsy live with uncontrolled seizures despite available treatments.[2] Delayed recognition of seizures and inadequate treatment increase a person's risk of subsequent seizures, brain damage, disability, and death.

About 40% of adults with epilepsy[3] and more than one-third of children and youth with special needs[4] rely on Medicaid for their health coverage. Many children and adults with epilepsy, and especially the rare epilepsies, rely on Medicaid HCBS. HCBS provides people with disabilities and chronic conditions the services and supports they need to live independently in their homes and communities, avoiding premature or undesired living in institutional settings. These services can – depending on the state and the waiver under which the person is receiving services – include supported employment, adult day care, round-the-clock care, services to support unpaid family or friends who are caregivers, home-delivered meals, non-medical transportation, and more.

Aug; 157:109852.; Data Research Center. 2022 National Survey of Children's Health. Accessed December 8, 2025.

[2] Kwan, P & Brodie, MJ. Early identification of refractory epilepsy. *N Engel J Med.* 2000;342(5):314-319. DOI: 10.1056/NEJM200002033420503.; Chen, Z., Brodie, M.J. et al. Treatment outcomes in patients with newly diagnosed epilepsy treated with established and new antiepileptic drugs: A 30-year longitudinal cohort study. *JAMA Neurol.* 2018;75(3):279-286. doi:10.1001/jamaneurol.2017.3949.

[3] Tian, N., Kobau, R., Zack, M.M., & Greenlund, K.J. Barriers to and disparities in access to healthcare among adults ≥ 18 years with epilepsy – United States, 2015 and 2017. Centers for Disease Control and Prevention Morbidity and Mortality Weekly Report. May 27, 2022; 71(21): 697-702.

[4] Medicaid and CHIP Payment and Access Commission (March 2023). *Medicaid Access in Brief: Children and Youth with Special Health Care Needs.* https://www.macpac.gov/wp-content/uploads/2023/03/Medicaid-Access-in-Brief-Children-and-Youth-with-Special-Health-Care-Needs.pdf.

Medicaid covers 70% of all HCBS in the U.S.[5] States are required to cover home health but other than that, states must pursue covering other Medicaid HCBS via waivers. Waivers can only be offered to specific populations, which creates caps on the number of people states can enroll and because of the high demand, waiting lists for services. In 2023, over 692,000 people were on wait lists for Medicaid HCBS.[6]

EFA and the wider epilepsy and disability communities are greatly concerned that the Medicaid changes and cuts included in P.L. 119-21 will mean reductions to HCBS and even longer waiting lists for people with epilepsy and other disabilities who need these services. Historically, when states have faced budgetary pressures, they have responded by cutting eligibility, benefits, and provider payments. For example, in 2009, Congress responded to the Great Recession with an increase in federal Medicaid matching funds. After that funding was reduced, every state and the District of Columbia cut spending to one or more of their HCBS programs between 2010 and 2012.[7]

We ask that the Senate Special Committee on Aging work to protect HCBS and increase access. For more information on the importance of HCBS, please see the attached stories of three people with epilepsy and their families which have been included and submitted with their permission. These are just a few examples of the many people with epilepsy who need these services.

Thank you again for your commitment to assisting older adults and people with disabilities. The Epilepsy Foundation of America looks forward to continuing to work with you. Should you have any questions, please do not hesitate to contact Roxanne Yaghoubi, Senior Director of Federal Relations and Policy, at ryaghoubi@efa.org.

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[5] Priya Chidambaram and Alice Burns, "10 Things About Long-Term Services and Supports," KFF, July 8, 2024, https://www.kff.org/medicaid/10-things-about-long-term-services-and-supports-ltss/ (accessed December 8, 2025).
[6] Alice Burns, Maiss Mohamed, and Molly O'Malley Watts, "A Look at Waiting List for Home- and Community-Based Services from 2016 to 2023," KFF, November 29, 2023, https://www.kff.org/medicaid/a-look-at-waiting-lists-for-medicaid-home-and-community-based-services-from-2016-to-2023/ (accessed December 8, 2025).
[7] Jessica Schubel, Alison Barkoff, H. Stephen Kaye, Marc Cohen, and Jane Tavares, "History Repeats? Faced With Medicaid Cuts, States Reduced Support For Older Adults And Disabled People," Health Affairs, April 16, 2025, https://www.healthaffairs.org/content/forefront/history-repeats (accessed December 8, 2025).

EPILEPSY FOUNDATION

Sincerely,

Laura Weidner
Chief Advocacy & Government Relations Officer
Epilepsy Foundation of America

EPILEPSY FOUNDATION

Medicaid HCBS Is the Lifeline: Why Federal Cuts Would Break Families Like Mine

My son Bennett is a young adult with an ultra-rare combination of complex neurological disabilities. He survived catastrophic epilepsy through a right hemispherectomy and lives with a VP shunt for hydrocephalus. His challenges are lifelong, and he requires ongoing physical, cognitive, and medical support.

Because of Medicaid Home and Community-Based Services (HCBS), Bennett is able to live at home, participate in his community, work part-time at a job he loves, and take college classes. HCBS provides the in-home care, respite, and long-term services that make this possible. Without HCBS, he could not safely live in the community.

We are a middle-income family, but the complexity and intensity of Bennett's needs exceed what any family could manage on its own. Each MRI, neurosurgical intervention, therapy, or support service is part of a lifelong care plan that requires continuity and expertise. Medicaid fills the gaps, providing essential in-home support, therapies, and services that keep him safe, stable, and able to thrive.

If federal Medicaid or HCBS funding is cut, our entire system of care collapses. There is no alternative. Institutional care is not only inappropriate for my son, but it is also largely unavailable and would cost the government far more. HCBS keeps families together and keeps medically complex individuals out of crisis.

We are already seeing caregiver shortages, shrinking services, and long waitlists. Cuts to HCBS would push families like mine past the breaking point and leave vulnerable individuals without the support they need to live safely at home.

I urge the Committee to protect and strengthen Medicaid HCBS.

- Please do not balance the federal budget on the backs of children and adults with significant disabilities.
- Medicaid HCBS is not optional. It is the lifeline that keeps people safe, supported, and in their communities.

Thank you for your attention to the needs of families like ours.

Our mission is to improve the lives of people affected by epilepsy through education, advocacy, research, and connection.

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24/7 HELPLINE **800.332.1000**

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HCBS, Lennox-Gastaut Syndrome, and an Everyday Life – Billy 39 years old, PA

June 14th is Flag Day. It is also the day that Billy's seizures started in 1990. There were two at a birthday party, a brief one in the Emergency Room, and ten myoclonic seizures on the ride home (although I didn't know what they were). Within a year I was told that my amazing 4-year-old toddler would not survive to be 6 because his seizures were so severe. Eventually he came to be diagnosed with a rare epilepsy known as Lennox-Gastaut Syndrome (LGS) that has impacted not only his life but the lives of everyone who loves him. His seizures are life threatening, bones break, cognition fails, pneumonia is frequent, and medication side effects impact daily life – including mood, function, and skills. Despite all of this, Billy wants a life like everyone else, and HCBS through a Medicaid Waiver offers him just that.

Billy requires 24/7 support and many medical interventions, but this does not mean that he is in bed or chair just watching the hours go past. No. Billy is an active participant in his life. With the support of his in-home staff, he is honing his reading skills, working on hobbies, attending self-advocacy workshops, preparing to speak for himself at doctor appointments, accomplishing necessary life skills such as keeping his room and his craft area neat, joining in games with friends and participating in zoom chats with extended family. Even better, just like his younger siblings, he has a girlfriend and goes on dates to restaurants and special events. He gives back to his community when he can, volunteering at local food banks, thrift stores, and other non-profits despite seizures that still occur daily even with four powerful seizure medications and two neuromodulation devices.

Everyone deserves an Everyday Life. EVERYONE. HCBS should support the opportunities that make an Everyday Life a reality. These supports offer people living with epilepsies the chance to go out and be safe, to live free from stigma, and to give back. It offers the support staff the opportunity to work in a rich and satisfying environment (and to pay taxes!). It offers Family Caregivers support, respite, and – hopefully- freedom from poverty and exhaustion. Without waiver, Billy would have a minimal life, and our family would be desperate. In fact, Billy may not even have survived to be 39 years old – and for that reason I will be eternally grateful to Pennsylvania's waiver system.

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HCBS Impact in William's Life

William was born with a genetic disorder, KCNQ2, with seizures beginning in the first days of his life. We didn't know the impact this would have on William's health and well-being let alone his adult life. William is now 26. He has lived a wonderful life with family and friends who adore him. The lab technicians at the local hospital where he gets his bloodwork done several times a year all know him. The same person who cut his hair when he was two years old still cuts his hair now. William loves music, swimming and all the local parks and stores he frequents. William is known, loved, embraced and welcomed wherever he goes.

As parents, we have had to continually navigate systems – healthcare, education, social services, learning along the way as they overlapped and intertwined. The importance of community is defined by the need of each individual, and for William, he is now in a residential home with peers in our community that is supported by the same agency that provided him with Birth to Three services. This is what we have chosen for now, but it is not a one size fits all for individuals with complex disabilities. There are many who would benefit by a medical model, which is a community in and of itself that provides much needed supports for people like William.

William thrives on love, stability, consistency, and dedicated caregivers, some of whom work several jobs to make ends meet. William's life matters.

Our mission is to improve the lives of people affected by epilepsy through education, advocacy, research, and connection.

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24/7 HELPLINE **800.332.1000**

Eytan's responses to 'Beyond Words' Panel Questions from June 1st 2025

Eytan Nisinzweig was one of four people from Abilis's STeP Program who participated on a panel and inspired the 150 people in the audience with their words of wisdom! Below are the questions and Eytan's typed responses. The iPad has an app that has a voice output feature that read his comments.

1. **Introduce yourself including your name, how long you have been typing, and share something(s) you want the audience to know about you.**

   Eytan typed: Hi, my name is Eytan and I have been typing for seven years. It has been the most exciting time of my life and has opened so many possibilities for me. I have a deeper connection with all of my friends and family. It has allowed me to teach other people about how to understand nonverbal autistic people. I also love music and playing the piano, one of my jobs is to play piano to children and I enjoy cultivating a love for music in them.

2. **What qualities do you think make a great facilitator/communication partner and how many facilitators /partners do you think would be good for a person to have?**

   Eytan typed: It takes good energy and determination it requires a lot of time and practice. If you can think you can type. Becoming a good communication partner is hard work but if there is motivation it will work. Communication partners are always welcome and the more facilitators the better. Partners are accesses and we need as much access as possible.

3. **What advice would you give a peer, a parent, or a professional who is unsure if typing is for real and worthwhile for them to try?**

   Eytan typed: My philosophy for typing is like anything else in life try it and see what happens. You may discover something beautiful.

4. **How has typing/spelling impacted your happiness and/or frustration levels?**

   Eytan typed: It has made my quality of life has changed drastically, I am now in the driver's seat and make so many more decisions about my life. My abilities are seen and can no longer be ignored. I am able to help others like me here in my community. It makes me feel like I have true purpose in life.

5. **What are ways that you are being an advocate for yourself and for this community in order to overcome some of the barriers that typers and spellers currently face?**

   Eytan typed: My goal has always been to learn how to eventually type independently but while I learn I know it is important to always keep good eye contact. I also always try my best to type during trainings and let people know how much this has changed my life. It also is important for me to have access to good facilitators so that I can advocate for myself. I think my family always tries to provide as many opportunities for me to communicate. Opportunities to communicate are always the best way to become an advocate. Thank you for giving me that opportunity today.

Outside Witness Testimony of
Meals on Wheels America

Submitted to the U.S. Senate Special Committee on Aging
Hearing: ***Aging in Place: The Impact of Community during the Holidays***

December 4, 2025

On behalf of Meals on Wheels America, we are writing to provide this outside witness testimony for the hearing, "Aging in Place: The Impact of Community during the Holidays," held on December 3, 2025. Meals on Wheels America is the national leadership organization representing more than 3,000 community-based senior nutrition programs operating in virtually every county across the country.[1] Our members deliver **251 million meals to more than 2 million seniors annually** and provide critical social connection and daily safety checks to older adults who are often living alone, homebound, or coping with mobility limitations and chronic health conditions. Together, we work toward a vision in which every older adult can age with nourishment, independence, and dignity.

End the Wait

We are amid an affordability crisis for low-income older Americans, which is hitting right at the holiday season, when struggles with loneliness and hunger are felt even more acutely. For millions of seniors, the holidays are the loneliest time of the year, as they face silent nights, silent weeks, silent months – even silent years – hoping someone will care. No senior should have to wait in isolation, struggling behind closed doors hoping for basic care like nutritious meals and moments of connection. That's why Meals on Wheels America launched the Silent Night campaign[2] to call attention to the widespread unmet need and build support to **End the Wait** for seniors who need Meals on Wheels.

Unfortunately, chronic federal funding shortfalls, a growing need for services for America's rapidly aging population, and increasingly high costs for food, fuel, and program operations limit the ability of local Meals on Wheels programs to reach the vulnerable older adults in need across the country. The challenges of senior hunger and isolation are being exacerbated now by delays for reimbursements to local Meals on Wheels providers due to the government shutdown[3], cuts to SNAP[4] and Medicaid[5] that will lead to benefit losses for many low-income older adults and high costs for food and essentials, making it all the more difficult for many to meet their basic needs.

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[1] Meals on Wheels America. "About." *Meals on Wheels America.* https://www.mealsonwheelsamerica.org/about/

[2] Ending Senior Loneliness and Hunger | Help End Silent Nights

[3] Government Shutdown: The Impact on Meals on Wheels

[4] SNAP Work Rules Strain Older Adults, States

[5] What's in the Budget Reconciliation Act of 2025 and What Does it Mean for Low-Income Older Adults' Access to Health and Long-Term Care? - Justice in Aging

According to the most recent Meals on Wheels America data, nearly one in three local providers have waitlists, and nearly 46,000 seniors are waiting nationally for services.[6] The typical wait is four months, and in some areas older adults have waited more than two years for the nutritious meals and moments of connection and care they need and deserve.[7] As one program leader poignantly expressed: "It's the worst feeling to have to tell someone, 'We have a waitlist.' You can't speak those words without feeling emotion because you're telling someone who's starting." Without additional federal investment and support, more providers will be unable to meet growing requests for help and will be forced to have such heartbreaking conversations with seniors in need they are not able to serve.

With increased funding and strong congressional backing for the OAA Nutrition Program, our nation can ensure that more of our vulnerable seniors receive the meals and social connection they need to remain healthy and independent at home. Ending the wait for services is essential to support aging in place for millions of older Americans who rely on Meals on Wheels. Meals on Wheels America urges Congress to swiftly reauthorize the Older Americans Act by advancing the bipartisan OAA reauthorization bill reintroduced in the Senate and providing emergency supplemental funding for the OAA Nutrition Program for FY26 to help address the widening crises of senior hunger and isolation, following the bipartisan call for a funding boost recently made by Representatives Vern Buchanan (R-FL 16) and Suzanne Bonamici (D-OR 1).[8]

Social Connections for Older Americans

While nutrition is central to our mission, the work of Meals on Wheels programs extends far beyond the delivery of food. Daily interactions with volunteers and program staff, which may be the only person a senior sees that day, provide meaningful and consistent social connection. These touch points reduce loneliness, contribute to improved health outcomes, support emotional well-being, and help identify emerging health or safety concerns before they escalate into emergencies.

Today, millions of seniors experience social isolation, leaving them at risk for a multitude of adverse and costly health issues. Studies show the highest rates of social isolation are found among older adults, putting seniors at risk for high blood pressure, heart disease, obesity, a weakened immune system, anxiety, depression, cognitive decline, Alzheimer's disease, and even

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[6] Meals on Wheels America, *Fact Sheet: The Crisis of Waitlists for Meals on Wheels*, accessed November 30, 2025, https://www.mealsonwheelsamerica.org/research/fact-sheet-the-crisis-of-waitlists-for-meals-on-wheels/

[7] Meals on Wheels America, *2024 Membership Impact Report*, August 2025, https://www.mealsonwheelsamerica.org/wp-content/uploads/2025/08/2024-Membership-Impact-Report_8.4.25.pdf

[8] Ahead of the Thanksgiving Holiday, Buchanan and Bonamici Lead Bipartisan Push to Strengthen Preventive Nutrition Services for Seniors | Press Releases | Congressman Vern Buchanan

death. Research demonstrates that social isolation among older adults leads to an extra $6.7 billion (about $21 per person in the US) in Medicare spending per year in 2012 dollars, associated with the expenditures of having high blood pressure or arthritis.[9]

Some of the most vulnerable seniors that the Older Americans Act serves, those who are frail, homebound, and socially isolated, rely on the home-delivered meal programs. Despite the well-established link between healthy aging and regular socialization, millions of seniors struggle to meet their basic human needs. Local, community-based organizations play a critical role in addressing the social and nutritional needs of our nation's older adults and the impact of these services on seniors' lives is powerful.

During the holiday season, when feelings of isolation often intensify, these interactions become even more significant. Community-based Meals on Wheels providers host holiday gatherings, deliver special meals, and provide thoughtful items such as blankets, winter supplies, pet food, and holiday cards and decorations. These small gestures serve as powerful reminders that older adults are valued and not forgotten during a time that can be especially difficult for those who are alone.

Across the country, Meals on Wheels programs have stories about the creation of deep and lasting connections during the holiday season and beyond.

- One senior in a creative-arts program offered by the CICOA Aging & In-Home Solutions shared: "This was a great time spent with people I now can call friends. I have painted pictures that taught me to step outside my box. Thank you for teaching me how to make something I can be proud to display and techniques I can share with my grandchildren."

- An older adult in a friendly-visit and call program run by KC Kosher Meals on Wheels described: "Before the visits started, I would go days without speaking to anyone. It felt like the world had forgotten me. Now, every week, I look forward to hearing that knock on the door or the phone ringing. It gives me something to smile about and reminds me that I still matter."

- And from MOW Central Indiana, a friendly-visit senior named Hope said it best: "Sometimes, all it takes is one person dropping by to remind you you're not alone."

[9] Lynda Flowers et al., *Social Isolation and Medicare Spending Among Older Adults*, AARP Public Policy Institute & Stanford University, November 27, 2017, https://www.aarp.org/medicare/high-price-of-social-isolation-study-2017/

These personal testimonies illustrate the powerful impact of Meals on Wheels, not just providing nutrition, but restoring dignity, joy, and meaningful human connection during a time when loneliness often intensifies.

The Case for Meals on Wheels and the Older Americans Act: Evidence on Senior Isolation
Our report, The Case for Meals on Wheels: An Evidence-Based Solution to Senior Hunger and Isolation, examined 38 studies conducted from 1996 to 2023 and consistently found that Meals on Wheels reduces loneliness and improves seniors' emotional, physical, and social well-being.[10]

Key findings include:

- **Reduced social isolation and loneliness:** Multiple studies found that home-delivered meals reduce feelings of loneliness, especially among older adults living alone. The simple, consistent human contact provided during meal deliveries, wellness checks, and friendly-visit programs is a critical safeguard against the harms of social disconnection.
- **Improved emotional well-being:** Participants reported feeling more hopeful, connected, and supported when receiving meals. Studies show that these regular social touchpoints directly improve mental health, helping prevent depression and emotional decline.
- **Reduced falls and increased safety at home:** Safety checks performed during meal delivery not only ensure older adults' well-being but also reduce risks associated with being isolated at home. Fewer falls and hazards mean fewer emergencies and greater confidence aging in place.
- **Reduced use of costly health care services:** Studies found that seniors receiving home-delivered meals, including socially oriented programs, experienced fewer emergency [11]room visits, hospitalizations, and readmissions. Preventing crises linked to isolation saves both lives and taxpayer dollars.
- **Increased ability to age in place:** Nearly all (92%) of home-delivered meal recipients report that Meals on Wheels helps them remain independent at home. Because isolation is a major factor pushing seniors prematurely into institutional care, social connection paired with nutrition is essential.[12]

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[10] Meals on Wheels America, *The Case for Meals on Wheels: An Evidence-Based Solution to Senior Hunger and Isolation* (Arlington, VA: Meals on Wheels America, 2023), https://www.mealsonwheelsamerica.org/thecase
[11] Meals on Wheels America, *The Case for Meals on Wheels*.
[12] U.S. Administration for Community Living, *2022 National Survey of Older Americans Act Participants*, accessed December 2, 2025, https://acl.gov

These outcomes underscore a simple but urgent truth: the consequences of senior isolation are costly and preventable, and Meals on Wheels delivers one of the most effective national interventions available today.

However, access to the critical lifeline Meals on Wheels services offer depends on congressional support for protecting Older Americans Act programs and ensuring increased federal funding to enable community-based providers to meet the profound social and emotional needs of our rapidly growing senior population.

The holidays spotlight the loneliness, hunger, and hardship too many older adults experience, and these challenges persist long after the decorations come down. This season, Meals on Wheels providers need additional federal support as they are doing everything they can to ensure no senior is left hungry or alone.

ABCDNJ - Medicaid - Full Production

I

WINNIE

I was sent to an institution at 16. I didn't feel free again for 22 years. I had no privacy,

No voice, and no control over my life. It felt like I had been forgotten. When I moved into a group home, I finally had my own room and people who listened to me.

I could make choices again. It was the first time I felt human in years.

EDWARD

You slept like in a dormitory with a bunch of other kids. If you didn't have a locker with a lock on it. They would steal your stuff from you.

PATRICIA

We've had other folks come out of institutions. They were allowed to urinate on their seats and their chairs, and nobody cared if they did.

They come to us and they're happy, they're smiling, they're trying to talk, they're in diapers, they have dignity. And you know, that's what it's all about, it's dignity.

LINDA

Basic human rights were not being met. We’re talking decades that it took people to get out of the institutions. There were many, many obstacles, and we can't go back there.

SANDY

If all of this went away, it would be devastating to see how people lived. They were treated like animals, chained to radiators. We don't segregate anymore. We're an all-inclusive community because we're not institutions. We're people living in communities, productive members of society.

JOHN

We're not gonna be able to care for him forever. He needs to have a place where he can be himself. We can't really provide the way we want to and need to.

KATE

So if we didn't have the DDD budget, we could never have afforded to have paid out of pocket. His speech grew and that happened because he's got the staff here that can encourage him in ways because they're not mom and dad. We would truthfully be in crisis if Paul wasn't part of these programs.

SPEAKER/MICHELE

Do you like living in your own house?

PAUL

Yeah.

SPEAKER/MICHELE

Do you remember when you moved out with mom and dad and you came here?

PAUL

Yeah.

SPEAKER/MICHELE

Were you happy to be here?

PAUL

Yeah.

SPEAKER/MICHELE

Who's your favorite staff?

PAUL

Doug. I love you!

JOHN

Before you start slashing budgets and just indiscriminately cutting stuff, hold on! You're talking people. You're talking souls. You're talking lives who have rights just like everybody else.

KATE

Where's a legislator who's gonna stand up for us or for our children? It's about knowing our son's cared for, but in a way that develops him and his abilities and his gifts that we could no longer do.

HELEN

I am so happy that they have some place for my child to go. I used to have to carry Justin around just to get him to different places, but he just needs someone to talk to. His father just passed. I want him to be able to go someplace where he can find some peace.

JUSTIN

I'm more thankful for the program because without this I don't know what I would do. It made my life better. I want to keep the program going as long as I can. I will feel depressed and nobody wants to feel depressed.

REGGIE

Chronologically, they may be of an adult age, but functionally, they're not. The program gives them a sense of independence. It allows for self-determination. It gets them out the house, otherwise they would be prisoners and jailed in their own homes. When you don't have such therapies, you do observe individuals regressing, and it's daunting to observe that.

GABBY

The support gives me leverage to help with my medical needs, a work environment, help out and take care of my son.

ROBERT

My job, it means everything. I love my job. It makes me feel like I have a life, ability to have some freedom. If I wasn't working, I'd be doing nothing.

INDIA

I've been working five years. I feel like I accomplished something. The way my life is now is better, better for me. Give me a great opportunity to support my kids.

SARA

I like coming to work because it's fun. It helps me be independent. I learn new skills. I like to teach people new things, how to cook, what to cook, the right way to cook, the right ingredients, follow directions, recipes.

SEQUANDA

If Medicaid was cut. I would be able to go out in the community. I wouldn’t have my housing.

DIANA

Employment gives me a purpose where I get out and be within my own community. I get a good job and I have a normal life with a disability.

EDWARD

Rent, it's kind of steep and the Social Security and stuff that helps out a whole lot. And if we didn't have Social Security or anything, we'd be up the creek without a paddle.



December 8, 2025

The Honorable Rick Scott
Chair
Senate Aging Committee

The Honorable Kirsten Gillibrand
Ranking Member
Senate Aging Committee

Dear Chair Scott and Ranking Member Gillibrand,

MomsRising submits the following statement for the record as part of the Senate Aging Committee hearing on "Aging with Purpose: The Positive Impact of Seniors in Today's Economy." This statement is to be submitted for the Senate Aging Committee hearing scheduled for December 10, 2025.

MomsRising is a grassroots organization with over one million members who are dedicated to protecting the health and wellness of our nation's children, families, older adults, and elders. Older adults and people with disabilities have the right to live with dignity, independence, and full inclusion in their homes and communities. Home- and Community-Based Services (HCBS) play a particularly vital role by providing the individualized supports people need to remain in their homes and participate in their communities. These services promote autonomy, improve health and well-being, and strengthen social and family connections.

For many families who have adults with disabilities, or aging family members, this shared hope for independence and inclusion can be a significant struggle without the right kind of support and services. HCBS, Centers for Independent Living (CILs), and other community-based supports—including those that help people thrive in education, employment, and civic settings—are often the difference between merely getting by and truly living full, self-directed lives.

When people receive robust community-based support, especially HCBS, they experience better outcomes, greater stability, and a higher quality of life. Investing in HCBS and the broader network of community services is not only the right thing to do; it is a cost-effective approach that benefits individuals, families, and our nation.

Below, we highlight stories from our MomsRising members across the country who shared the importance of Home- and Community-Based Services, as well as the profound impact these supports have had on their lives.

- "My 91-year-old mother has pulmonary fibrosis, requires 24-hour oxygen, and in-home care. It is breaking her bank, even though she is considered well off. As we treasure our elders, we need to make their lives comfortable—as end-of-life ordeals lie in store for



each of us. Caregivers need a living wage, and figuring this all out is a tremendous burden!" - M., Pasadena, CA

- "When my aging father-in-law needed care, everyone we talked to advised us to put him into a care facility, and to not take him into our home because it's just too much work and will make us miserable. But we refused to allow him to die alone or with strangers. We had one-year-old twins to care for, plus a senior citizen who could no longer stand up without assistance. Caring for him was the wisest thing I have ever done! But Medicare assistance was minimal and made this so much more difficult. Please make this possible for all families. We need skilled and non-skilled support for all families who are willing to care for loved ones." - Michal, Santa Barbara, CA

- "As a person with cognitive difficulties from a skull fracture, and the fatigue of lymphoma and myalgic encephalomyelitis, I don't want to even think about my life without the crucial, essential assistance of In-Home Support Services. I would not be making it." – Tina, Bolinas, CA

Further, protecting immigrant communities across the country is crucial to maintaining the home care workforce. Immigrants make up between 32 percent and 40 percent of workers in home care settings, and they are a crucial part of our communities. There is already a shortage of home care workers in the U.S., and it's essential that immigrant home care workers can continue to work in their communities.

Ensuring these long-term care services are available, accessible, and sustainable is essential to honoring the rights and aspirations of older adults and people with disabilities and to building communities where they can live with independence and full inclusion. Therefore, **MomsRising urges Congress to take action to improve our long-term care system to enable people with disabilities, as well as older adults, to stay at home and thrive in their communities.**

Sincerely,

Felicia Burnett
National Director, Storytelling Innovations and Health Care
MomsRising Together & MomsRising Education Fund

SUPPORTING SENIOR HEALTH AND INDEPENDENCE WHILE SAVING MONEY

MEALS ON WHEELS AMERICA | END the WAIT™

For more than 50 years, Meals on Wheels has set the gold standard as an evidence-based public-private partnership that effectively addresses the issues of senior hunger and isolation while providing a proven significant return on investment in the form of health care savings.

But with growing demand and rising costs, many seniors are left waiting for nutritious meals and moments of connection. And while they wait, they're more likely to end up in the hospital or a long-term care facility. The need has never been greater, but together, we can End the Wait.

HUNGER AND ISOLATION PUT SENIORS AT RISK FOR COSTLY HEALTH ISSUES

ALMOST 95% OF OLDER ADULTS HAVE AT LEAST ONE **CHRONIC CONDITION**, AND NEARLY 80% HAVE TWO OR MORE.

Food insecure older adults experience worse health outcomes than food-secure seniors, with greater risk for:

- HIGH BLOOD PRESSURE
- HEART ATTACK
- DIABETES
- DEPRESSION

Older adults have the highest rates of **social isolation**, putting seniors at risk for:

- HIGH BLOOD PRESSURE
- ANXIETY AND DEPRESSION
- COGNITIVE DECLINE
- DEMENTIA

Federal funding shortfalls for Meals on Wheels end up costing the government and taxpayers more due to costly health care and long-term care expenses **THAT COULD HAVE BEEN PREVENTED**.

WHEN ADJUSTED FOR INFLATION:

$75 BILLION

SENIOR MALNUTRITION costs an estimated $75 billion a year in health care costs.

$98 BILLION

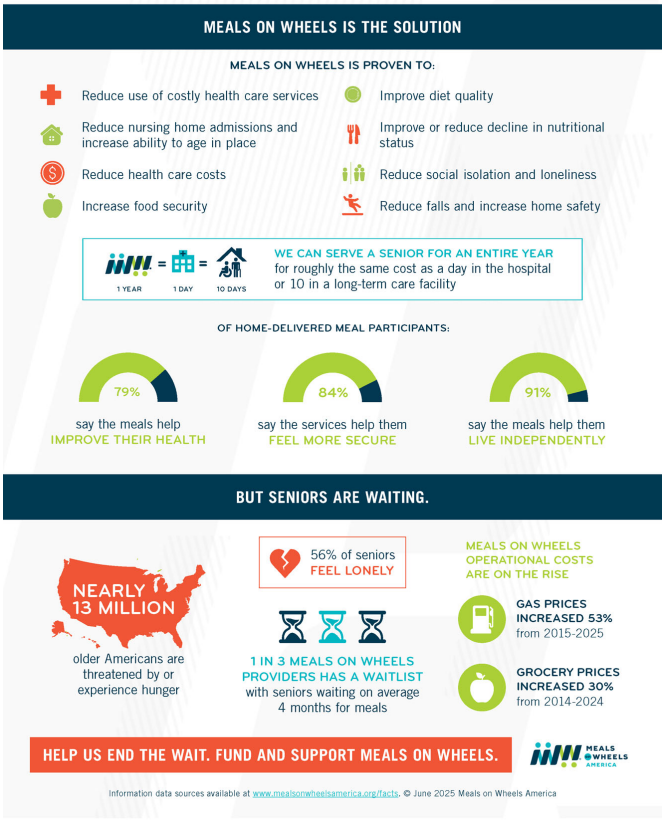
OLDER ADULT FALLS cost the U.S. health care system $98 billion a year, with most of the cost paid by Medicare.

$9 BILLION

SOCIAL ISOLATION costs Medicare an estimated $9 billion annually.

The estimated economic value of family caregivers' unpaid contributions is approx.

$600 BILLION


MEALS ON WHEELS IS THE SOLUTION
MEALS ON WHEELS IS PROVEN TO:
Reduce use of costly health care services
Reduce nursing home admissions and increase ability to age in place
Reduce health care costs
Increase food security
Improve diet quality
Improve or reduce decline in nutritional status
Reduce social isolation and loneliness
Reduce falls and increase home safety
1 YEAR = 1 DAY = 10 DAYS
WE CAN SERVE A SENIOR FOR AN ENTIRE YEAR
for roughly the same cost as a day in the hospital or 10 in a long-term care facility
OF HOME-DELIVERED MEAL PARTICIPANTS:
79%
say the meals help IMPROVE THEIR HEALTH
84%
say the services help them FEEL MORE SECURE
91%
say the meals help them LIVE INDEPENDENTLY
BUT SENIORS ARE WAITING.
NEARLY 13 MILLION
older Americans are threatened by or experience hunger
56% of seniors FEEL LONELY
1 IN 3 MEALS ON WHEELS PROVIDERS HAS A WAITLIST
with seniors waiting on average 4 months for meals
MEALS ON WHEELS OPERATIONAL COSTS ARE ON THE RISE
GAS PRICES INCREASED 53% from 2015-2025
GROCERY PRICES INCREASED 30% from 2014-2024
HELP US END THE WAIT. FUND AND SUPPORT MEALS ON WHEELS.
MEALS ON WHEELS AMERICA
Information data sources available at www.mealsonwheelsamerica.org/facts. © June 2025 Meals on Wheels America

NAELA
National Academy of Elder Law Attorneys

1577 Spring Hill Road, Suite 310 // Vienna, Virginia 22182
naela@naela.org // 703-942-5711 // www.NAELA.org

Statement
of the
National Academy of Elder Law Attorneys
for the
Special Committee on Aging
of the
United States Senate
"Aging in Place: The Impact of Community During the Holidays"
December 3, 2025

On behalf of our more than 4,000 members who are attorneys representing older Americans and individuals with disabilities, the National Academy of Elder Law Attorneys (NAELA) writes to express our strong support for funding home and community-based services (HCBS) that allow older adults and individuals with disabilities to remain active in their communities rather than entering institutional care. NAELA is the leading professional association dedicated to improving the quality of legal services for older Americans and individuals with disabilities. With 31 active state chapters, NAELA provides elder and special needs law attorneys with education, advocacy, community, and the resources they need to better serve their clients.

HCBS programs are essential to allowing older adults and individuals with disabilities to choose where and how they age. While most people who qualify for HCBS face physical, cognitive, intellectual, and mental health disabilities that require an institutional level of care, HCBS give them the option to have that care at home through a wide variety of medical and personal care services, along with an array of other supports, such as adult day care, home-delivered meals, home modifications, caregiver supports, transportation, and supported employment. These services allow them to live independently, with their families or in their communities, instead of in nursing homes or other institutions. This is especially true for married couples, who may each have different needs but who can remain living together through the various supports that HCBS care offers, rather than be separated into one or more institutional care facilities. By allowing individuals to stay in their own homes or other community-based settings, supported by their families and friends, HCBS programs promote their mental well-being and overall health.

Specifically, HCBS have been shown to reduce unnecessary institutionalizations, hospital readmissions, and other undesirable outcomes; by doing so, HCBS reduce hospital and nursing home expenditures for states and the federal government. However, because

Medicare and private health insurers do not cover HCBS, and private long-term care insurance is prohibitively expensive for most families, Medicaid is often the only feasible source of coverage for HCBS, serving as the primary payer for more than two-thirds of HCBS in the United States. States and the federal government have made great strides in increasing the use of HCBS over institutional care in recent years. However, HCBS programs face new challenges with passage of the federal budget reconciliation law (P.L. 119-21) this summer, which is expected to result in almost $1 trillion in cuts to federal Medicaid spending over the next 10 years nationally. As a result, states will be forced to consider difficult changes to their Medicaid programs in order to absorb the funding cuts. HCBS programs are particularly vulnerable to Medicaid cuts, which could come in the form of reduced benefits, reduced eligibility, fewer program slots and longer waitlists for services, and provider payment cuts that could exacerbate existing HCBS access issues and workforce challenges. In fact, when faced with budget shortfalls during the Great Recession, every state cut HCBS funding in some way. Although HCBS are considered optional services, they are anything but that for older adults and individuals with disabilities who face the prospect of moving from their home in the community surrounded by family and friends into an institutional care program where they may know no one.

Cutting HCBS programs would not just be devastating for the thousands of individuals who depend on these services; it would ultimately increase both state and federal Medicaid costs and further strain the nation's nursing facilities, which are already facing staffing shortages and other challenges. According to a recent analysis by LeadingAge LTSS Center @UMass Boston, cuts to HCBS programs could lead 2.8 million people 50 or older to seek institutional care rather than continuing to receive the HCBS they are receiving in 2025. The same study found that a 15% cut to HCBS expenditures would result in $467 million in increased nursing facility expenditures annually, a 30% cut in HCBS expenditures would result in $943 million in increased nursing facility expenditures annually, and a 45% cut in HCBS expenditures would result in $1.7 billion in increased nursing facility expenditures annually.

With 10,000 Americans turning 65 each day, the need for HCBS is only likely to grow in the coming years. HCBS offer a lifeline to thousands of older adults and people with disabilities and their families — keeping them out of institutions, allowing them to remain valued members of their communities, and preserving federal and state Medicaid dollars. We appreciate the committee's continued interest in HCBS, and we look forward to working with you to serve America's older adults and those with disabilities by supporting programs such as HCBS that enable them to live their lives with independence and dignity.



Submitted Written Testimony From
The National Disability Rights Network For
The Senate Special Committee On Aging Hearing On
Aging in Place: The Impact of Community during the Holidays
December 3rd, 2025

Chairman Scott, Ranking Member Gillibrand, and other members of the committee, thank you for convening this hearing on an issue that is critical to people with disabilities and older adults. Community is where individuals want to live, access services, work, learn, and participate fully in all aspects of society.

The National Disability Rights Network (NDRN) is the non-profit membership association for Protection and Advocacy (P&A) and Client Assistance Program (CAP) agencies operating in all 50 States, the District of Columbia, U.S. Territories, and a P&A and CAP affiliated with the Native American Consortium, which includes the Hopi, Navajo, and San Juan Southern Paiute Nations in the Four Corners region of the Southwest.

P&A and CAP agencies are authorized under various federal statutes to provide legal representation, advocacy services, and to investigate abuse and neglect of individuals with disabilities in diverse settings. Collectively, they form the nation's largest provider of legally based advocacy services for people with disabilities.

Community inclusion is essential for people with disabilities and older adults because:

- It reduces isolation which lowers the risk of abuse, neglect, and financial exploitation;
- It ensures access to tailored resources and services while promoting awareness of rights, and
- It fosters shared experiences, peer support, and a sense of belonging through inclusive activities that encourage engagement and participation.

The P&A/CAP Network advocates for all aspects of community living: education, accessible housing, employment, and transportation, and ensures services are delivered in the most appropriate integrated setting. NDRN and the P&A/CAP Network collaborates nationally and locally with organizations such as Independent Living Centers, Developmental Disabilities Councils, University Centers for Excellence in Developmental Disabilities, and others to achieve a society where people with disabilities are fully included and recognized as integral members of their communities.

820 FIRST STREET NE, SUITE 740 • WASHINGTON, DC 20002-4243
TEL: 202.408.9514 • FAX: 202.408.9520 • TTY: 202.408.9521
WEBSITE: WWW.NDRN.ORG • E-MAIL: INFO@NDRN.ORG

Each year, P&A agencies submit Program Performance Reports (PPRs) that demonstrate the impact of their work. While these reports are not standardized, they consistently show how P&As advance community integration for people with disabilities.

For example, in 2024:

- Over 2 million individuals received "appropriate community based services or AT devices and services that promoted independence and integration" through programs such as the Protection and Advocacy for Individuals with Developmental Disabilities (PADD), the Protection and Advocacy for Individuals with Traumatic Brain Injury (PATBI), Protection and Advocacy for Assistive Technology (PAAT), and Protection and Advocacy for Voter Access (PAVA) programs.

- More than 90 thousand people with disabilities were also "able to remain in their own homes" through the work done in those programs.

- Under the Protection and Advocacy for Individual Rights (PAIR) program, 29% of clients served were aged 60 or older, and 79% of all PAIR clients lived in the community (independently, in a parent or family home, or in a community residential home living arrangement) rather than institutions.

Community inclusion is not just a goal; it is a right and a necessity. The P&A and CAP Network is at the forefront of ensuring these rights are realized across all areas of life: education, employment, housing, transportation, healthcare, etc. We work every day to make sure that people with disabilities and older adults can live with dignity, independence, and fully participate in society.

We appreciate the committee's attention to this issue and look forward to continuing our work together to build a society where inclusion is not just an aspiration, but a reality for all. Should you have any questions, please feel free to reach out to Eric Buehlamnn, Deputy Executive Director for Public Policy at eric.buehlmann@ndrn.org.



December 8, 2025

Senator Rick Scott
Chairman
Special Committee on Aging
United States Senate
G16 Dirksen Senate Office Building
Washington, D.C. 20510

Senator Kristen Gillibrand
Ranking Member
Special Committee on Aging
United States Senate
628 Hart Senate Office Building
Washington, D.C. 20510

Dear Chairman Scott, Ranking Member Gillibrand, and Members of the Senate Special Committee on Aging:

Thank you for the opportunity to submit this statement for the record on the critical importance of community living for people with disabilities and older Americans. The American Association of People with Disabilities (AAPD) is committed to ensuring that all people with disabilities can live, work, and fully participate in their communities. Community living is not only a civil right—it is the cornerstone of independence, dignity, and opportunity.

Medicaid is the largest provider of long-term services and supports (LTSS) for people with disabilities. Every dollar invested in affordable healthcare and home- and community-based services (HCBS) creates jobs, reduces reliance on costly institutional care, and keeps families together. Research from the Kaiser Family Foundation shows that institutional care costs an average of $11,000 more per recipient than HCBS. Although institutional care is more costly, outcomes for people receiving this care are worse. People in institutional care experience faster and greater functional decline, worse health, and shorter life spans than people receiving LTSS in community settings. Yet because HCBS remains an optional benefit in Medicaid—and because the program maintains an institutional bias—Americans with disabilities of all ages are often forced into institutional settings to receive care, or they wait years for access to community-based services, forcing individuals and their families into impossible choices that no one should ever have to make.

The impending Medicaid cuts required by H.R. 1 threaten to deepen this crisis. History shows that when states face shortfalls, HCBS—particularly consumer directed home and community based services —are among the first to be cut. Even prior to the H.R. 1 cuts taking effect, disability advocates in Maryland, New York, and other states are pushing back against significant cuts to consumer-directed HCBS programs in the wake of state budget deficits. Medicaid is already underfunded, and states already struggle to meet the demand for Medicaid

HCBS amongst their citizens. Forty states have Medicaid HCBS waiting lists, upon which people wait three and half years to receive services. As the primary payer for LTSS in the United States, investments in Medicaid have a direct impact on the wages earned by the direct care workforce - personal attendants, direct support professionals, home health aides and more. Our nation is currently experiencing a severe shortage within the direct care workforce. Direct care professionals, who are disproportionately women of color, immigrants, and often people with disabilities themselves, earn wages so low that nearly one in four relies on Medicaid for their own healthcare. Sustaining and strengthening HCBS means stabilizing this workforce and ensuring continuity of care for millions of Americans.

The care economy is core national infrastructure—every bit as essential as roads, bridges, and broadband. It makes employment, education, and full community participation possible. Every day, more than 10,000 Americans turn 65, and nearly 40% have or will develop a disability requiring LTSS. Yet few have the resources to pay for services like personal care, homemaking, transportation, employment supports, or respite care out of pocket. These supports are often unavailable through private insurance and are inconsistently accessible through Medicaid. Today, the demand for community-based services far exceeds the system's capacity.

We are also gravely concerned about staff reductions at the Administration for Community Living (ACL), the only federal agency charged with overseeing community living programs, services, and supports for older Americans and people with disabilities. This includes Area Agencies on Aging, Centers for Independent Living, as well as oversight of the Developmental Disabilities Assistance and Bill of Rights Act programs—including State DD Councils, University Centers for Excellence in Developmental Disabilities, and Protection & Advocacy programs. These entities not only protect the rights of older Americans and Americans with disabilities but help states build the infrastructure necessary for community living.

We have included stories collected from people with disabilities from across the country about how important community living and the programs, services, and supports that make community living possible are to their ability to live, work, and thrive as an addendum to this statement.

The ability to receive support while living at home promotes independence, enhances physical and mental well-being, improves long-term outcomes, and saves taxpayer dollars. Congress must preserve and expand funding for Medicaid HCBS, strengthen the direct care workforce, protect aging and disability programs at ACL, and ensure that community living is not a privilege for some but a right for all.

Thank you again for holding this hearing and for your attention to these issues. Please do not hesitate to contact me at mlewis@aapd.com or (540) 447-9438 with any questions or to request additional information.

Respectfully submitted,



Michael Lewis
Vice President of Policy
American Association of People with Disabilities

Statement for the Congressional Record
Submitted to the U.S. Senate Special Committee on Aging
On Behalf of the National Task Group on Intellectual Disabilities and Dementia Practices
(www.the-ntg.org**)**

As a national advocacy organization working with thousands of families across the United States, we at the National Task Group on Intellectual Disabilities and Dementia Practices hear every week from parents, siblings, and caregivers who are struggling to find help when an adult with an intellectual disability begins to show signs of dementia. Their stories are remarkably consistent—*and deeply troubling*. Families describe watching a loved one lose skills, become confused or withdrawn, or suddenly struggle with daily routines, yet having nowhere in their community to turn for a dementia assessment by someone who understands lifelong intellectual disability.

For adults with intellectual disability—especially those with Down syndrome, who face exceptionally high risk for Alzheimer's disease—dementia often looks different than it does in the general population. Assessment requires specialized knowledge, adapted tools, and time for careful evaluation of changes from lifelong baseline functioning. Unfortunately, such expertise is scarce, and many families are left to navigate a system that is not designed for them.

Across nearly every state, we hear the same challenges:

- **Primary care providers lack training** in how dementia presents in adults with intellectual disability. Many mistakenly attribute new problems to the person's lifelong disability instead of recognizing early dementia.
- **Neurologists and geriatricians often decline referrals** because they feel unprepared to assess individuals with intellectual disability.
- **Waitlists for the few knowledgeable clinicians stretch many months**, during which caregivers face crises without guidance.
- **Families receive no road map after a diagnosis**, leaving them to piece together supports, often after preventable emergencies—falls, wandering, dehydration, or caregiver burnout—force more costly interventions.

The result is predictable: delayed diagnoses, unnecessary hospitalizations, premature institutionalization, and immeasurable suffering for both individuals and their families.

Yet this is not an unsolvable problem. Families tell us that when they *can* access dementia-capable assessments and post-diagnostic guidance—often through disability organizations or rare specialized clinics—they finally learn what changes to expect, how to adapt their home, what medical evaluations are needed, and how to keep their loved one safely in the community. These programs prevent crises, support caregivers, and ensure dignity in aging.

Unfortunately, access is the exception—not the norm.

We believe the Older Americans Act (OAA) offers a critical opportunity to address this national gap.
Connecting HCBS structures with the aging network would be one solution. Requiring State Units on Aging and Area Agencies on Aging to maintain up-to-date, accessible information on community-based dementia diagnostic resources—and to coordinate appropriate post-diagnostic supports—would transform the landscape for families who currently have nowhere to turn. These would be coordinated with HCBS entities. Such a requirement would:

- Establish a reliable statewide entry point for families seeking evaluation and guidance.
- Spur partnerships between aging services, disability organizations, and health systems.
- Ensure equitable access, regardless of ZIP code, income, or disability service affiliation.
- Prevent costly crises by connecting people earlier to dementia-capable supports.
- Reinforce the OAA's mission: enabling older adults and people with disabilities to live with dignity, independence, and full participation in their communities.

Families should not need to become medical experts, systems navigators, and crisis managers simply to obtain a dementia assessment. As the population of older adults with intellectual disability grows, this issue will only become more urgent.

On behalf of families nationwide, we respectfully urge the Committee to recognize the importance of accessible, community-based diagnostic and post-diagnostic dementia resources for adults with intellectual disability—and to consider strengthening the Older Americans Act to ensure these services are available, coordinated, and clearly identified in every state.

Thank you for including our perspective in the congressional record and for your leadership in advancing community living for all older adults and people with disabilities.

Dr. Matthew Janicki
Co-President
National Task Group on Intellectual Disabilities and Dementia Practices
www.the-ntg.org
PO Box 861, Rockport, Maine
janickimp@gmail.com

December 4, 2025

Submitted on behalf of the Arc

ALABAMA

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to us because there is no better way to help my child with a disability learn the value of contributing to society while he experiences the freedom of choice and responsibility of independence. My 27 yo son, Colby has overcome so many challenges to get to where he is now that his appreciation for community is solid and rooted in determination. Colby has CP and lives with 2 other roomates who also have disabilities. They live an hour away from us in a rental home near his work. He works pt and commutes using his electric scooter. He stops to chat with neighbors as he comes and goes and enjoys church activities with his same aged non disabled peers. While he graduated from a post secondary program for young adults with intellectual or developmental disabilities, he decided to continue his learning and attended a graduate training program through an accredited Bible college. Colby grew to love the campus and town of Tuscaloosa so much that the thought of moving back home to live with mom & dad was less appealing than he'd have ever imagined. He worked hard for years to save money displaying his strong work ethic and capacity for obtaining personal growth. Colby will tell you, he's living his best life alongside family and friends. His community has embraced his love of nature and his passion to learn more about life. He participates in the local BEST BUDDIES program, Unified Olympics and volunteers in local outreach ministries with his church. Colby & his roomates are accomplishing great things and living well in the community they chose. You can see more about Colby's contributions to the community here : https://youtu.be/00ahyKABIAw?si=3m9uniUF0HtG_1Hm The Colby Act was passed in August of 2023 and has led many to a place of much needed support from within their own communities. Colby enjoys telling his story and pointing people toward Community Inclusion.

Regards,

Kim Spangler

1062 Eagle Nest Cir

Birmingham, AL 35242

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I deserve it. Just like anyone else.

Regards,

Candace Rose

1421 47th St Ensley

Birmingham, AL 35208

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because everyone deserves a equal chance

Regards,

Kenneth Thrash

70 Whispering Pines Cir

Wetumpka, AL 36092

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because as an 84 year old Senior I need special services to accommodate the physical changes of aging; self-grooming; walking with a cane & other assist devises; difficulty to access transportation (driving is a chore); shopping for groceries is tiresome & costly; feeling safe & secure at night, etc.

Regards,

Frances Jones

1023 Uster St

Mobile, AL 36608

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I live with brittle Type 1 Diabetes and Progressive Multiple Sclerosis. Both have also allowed other conditions to attack my body (with hardly any ability to fight things off): chronic fatigue, chronic anxiety, depression, peripheral and autonomic neuropathy, radial palsy in my hand, asthma, chronic obstructive pulmonary disease, OCD, and more. That is 8 of my 23 chronic conditions that I have had since born in 1964.

I go to about 6 doctors every 3 months for checkups. And there have been times when me MS has been so active that I could barely walk or get out of bed, not make food for myself, not get to the Dr. For 25 years or so my ability to fight off colds, illnesses, etc has been very difficult due to very, very low White Blood Cell counts. But in the past 4 years I was put on a new medication for MS which doesn't wreck my blood count.

The home health services that Part A on my card provided is amazing. I fell in a hallway at my house in 20176 fracturing part of my left leg and breaking another bone in half. After spending a week in the hospital, and 6 weeks healing in a nursing center. When I got home, for 2 month had my rehab exercises in my den. Part A took care of it all. It provided nurses and physical therapists to come help me reuse my legs and ankles/feet. They also assisted in getting hand bars to put in rooms/halls.

In 20221/22 I moved to a retirement home. In January 2023 I had problems of falling one night, due to an MS/diabetic condition.

My head hit a bookshelf hit my head and crack on my skull. And MS flaired up more because of the stress. Again, Part A provided me with nurses and therapists to assist me in balance, walking, standing, eating, bathing. And they assisted with grab bars around my apartment. They stayed with me for about 3 months, until I was able to walk and stand without trouble.

Home and community based services for keeping health working right is a wonderful thing for us to have. For all cities and towns to be able to take part in when needed. Otherwise, people would be spending lots of money, which they may not have, on staying in a nursing home, the hospital, etc for help, or not getting assistance.

Regards,

Melanie Felker

Huntsville, AL 35803

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

-

Regards,

Peter Gebhardt

300 N Water St

Mobile, AL 36602

Submitted on Friday, December 5, 2025

Dear Members of the Special Committee on Aging,

My son, Josh, has Duchenne Muscular Dystrophy, he is 34 now. Our family have been following the research of this awful progressive disease for many years and Josh has benefited from improved treatments due to the research but nothing has stopped the progression of DMD and the devastating weakness it has caused.

Josh thinks often about his future, he still has hope. Please don't cut HCBS funds. If you do you'll end Josh's hope and others that suffer from DMD of a future. Josh has been a warrior since he was a little boy… fighting through his anxiety as his body grows weaker and his peers grow stronger.

He is wheelchair bound and needs assistance with all personal and medical care but he fights on! You have no idea of the courage he has shown. I'm calling on you to match his courage and support the Medicaid medical and HCBS programs that have allowed him to benefit from new treatments, go to college and be employed.

Regards,

Barbara Del Rio

412 Matzek Dr

Birmingham, AL 35226

ALASKA

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because everyone needs support in life, at one point or another. For some, it's help thriving, for others it can mean literal survival.

Since losing our Dad in late 2022, life has become increasingly difficult. We've realized that our Mom is declining cognitively. She relies on monthly survivor's social security checks, but it doesn't cover her medical bills and medications. We've just learned that the 340B care card program she uses to cover the outrageous cost of her meds are no longer available starting January 1st 2026.

In July of 2024, after several months of unresolved health issues, my 12 year old son was diagnosed with Crohn's disease. Life has not been fun for him. He needs very expensive infusions every 6 weeks to manage symptoms and keep the inflammation from progressing. It's been extremely challenging to balance work and time with my family. I've been trying to navigate resources for paid family care givers, but it's looking bleak. There's so much more to our story, including my own health issues, being BRCA1GENE positive.

Our lives are greatly impacted by these programs. They are vitally important to me and my family.

Thank you for your time.

Regards,

Heather Ogle

34395 Misty Morning Ave

Sterling, AK 99672

ARIZONA

Submitted on Wednesday, November 19, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I enjoy being an active member of my community. I want to live with my parents in my parents' home. HCBS enables me to live with my parents, volunteer, and attend online college. I am able to utilize my skills and my education for advocating for people with disabilities. I love attending community events. I love to participate in adaptive recreation activities. HCBS enables me to live a wholesome and fulfilling life.

Thank you for your consideration.

Regards,

Sarvesh Chandran

2373 E Waterview Pl

Chandler, AZ 85249

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because some aren't able to work.

Regards,

Debra Cook

6702 E Glenna Ct

Prescott Valley, AZ 86314

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we look out for eachother.

As a disabled elder, it has been the help of the State of Arizona which helped while raising my children to be productive, and educated members of society. My husband, legally blind, and I have been living within our SSD, and now SSI income, being off-grid and frugally surviving while raising our 3 children to become better educated. We still struggle, yet hold our family in high standings for helping others who are less fortunate than ourselves.

Regards,

Cynthia Christiansen

315 W Valencia Rd # 23521

Tucson, AZ 85734

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because people and faamilies of people with disabilities need your help to live a safe and healthy lifestyle, they need advocates, without them they would be silenced, oppressed anf the consequences would not only be demeaning but catastrophic.

Regards,

Therese Phipps

600 E Bromley St

Tucson, AZ 85704

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me

Regards,

Guadalupe Quintana

906 E 16th St

Douglas, AZ 85607

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I saw what can happen in a group home. My daughter was unfairly targeted by DCS, because she had so many hospitalizations when she was a teenager. ABC News shared our story on both November 21st 2024 and in October, 2025, as a part of an ongoing series of exposing the deaths of children from group homes. I left a career as a teacher after 17 years in 2020, because there were not adequate caregivers to care for my daughter. We just settled a lawsuit with the state last year. I spent days at the AZ State Capital with my daughter and other families speaking about and supporting the parents as paid caregivers program that Livingston from LD28 was targeting for cuts. A billion dollars has been spent on ESA vouchers, which started out as just for special needs families was switched in 2022 by the AZ legislature to include any family and by former governor Doug Ducey, which has had widespread fraud due to the AZ Department of Education Superintendent Tom Horne not verifying money spent under 2,000, which after review, showed wasteful spending on non educational items. So, not only is what the federal government provides essential because it's 70 percent of our funding, but it is why I am running for AZ House of Representatives. In the long run, more money is saved by keeping disabled people independent living in their own home, then by placing them in facilities that tend to have high turnover and is more costly than having them in their own family homes.

My daughter is 24 and has issues communicating basic needs, so she cannot work a job. She will always require round the clock care and supervision. Cutting funding that goes to that care is beyond cruel and thoughtless. Our veterans, elderly, and disabled fall into a category that needs federal funding and that BBB sets out to put families and adults like my daughter in precarious situations of how to maintain quality of care for them. Republicans claim to be the party that supports families, but they don't want to care for them once they born and apparently, even as adults and don't see the hardship that this will cause people with disabilities and families. Families are already seeing loss of services, loss of providers, and I need direct providers that can care for my daughter.

I struggled as a single mom, educator, and mother of a high needs nonverbal child, but now I am aging and I afraid of the impacts of these cuts will have on her, our families, other families, and companies that provide support and care for her. The impact that cuts to Medicaid will have for adults like my daughter and others will have extremely negative

impacts as it was challenging finding caregivers before the cuts and we already see people quitting.

Please do not do this to families and think about how you are hurting Americans. It took so long for rights to be given to the disabled and now Congress just wants to hurt disabled adults who cannot work. How is that making America great?

Regards,

Christine Scianna

15928 W Custer Ln

Surprise, AZ 85379

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am an advocate for people with special needs. The need all the services they can get to be able to live fulfilling lives. They cant afford two loose anymore services as they have already lost s many in the past. If anyone deserve this funding it is our special needs community.

Regards,

Juanita Gonzalez

727 N Main St

Cottonwood, AZ 86326

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am the mother and guardian of young woman now 28 years old, who was born with a rare chromosome anomaly. This is anomaly greatly affected her cognitive, emotional and psychological development to the point of making her unsafe and unsteady in the world. I have advocated for her to receive services in the community and in her home to help her live an independent and safe life. She contributes back to the community by volunteering, with support from her staff. She is happy and is at peace within herself because she has the support from home and community based

services. She would be either hospitalized or dead if these services were not in place I am grateful that I was able to advocate for her to receive the support she absolutely needs.

Regards,

Ché Leone

345 Concho Dr

Sedona, AZ 86351

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because some people need a little supervision to help them make it through this life.

Regards,

Patricia Vance

111 S Church Ave

Tucson, AZ 85701

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter works in a dementia center and tells me every day that she would never put me in a place like that, but I have lived with a failed back fusion for over 25 years already. There is no hope of it ever getting better, but sadly I will end up in a wheelchair needing help instead. We will need the help of the state, because I am on Medicare now. I don't see that changing anytime in the future.

Regards,

Kristina Mitschke

11270 W Folsom Point Dr

Marana, AZ 85658

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

My experience with community and home based services - and the System in general - has not been very positive. In fact, I'd go so far as to say they are the cause of much distress, which only seems to be getting worse with time. Frankly, what community and home based services?

The services I have received, have primarily proved to be wrought in bureaucratic processes and delays. Which, have caused frustration and exacerbation of symptoms. The System has been harmful when it's supposed to be helpful. Even the clubhouse model of peer support has become a much less helpful environment than it used to be. The last time I reached out, nobody responded

I was designated SMI (Serious Mental Illness) after being assaulted and sustaining a head injury. When in fact this is a mis- categorization. As, I have been diagnosed with autism and a history of trauma. These are not inherently severe psychiatric disorders. As a result, I was subjected to forced, unnecessary and contraindicated court petitioning, psychiatric evaluation, treatments and medications that have caused much harm. This could have all been avoided, had I been given due process, if legal procedural protections has been afforded, if I'd received notification of my rights, and if someone would just listen to me.

With the autism, it is best to allow me time to process things instead of just putting me on the spot to develop ISP's, etc. Plus I probably shouldn't even be in the mental health system. I'd probably be a better candidate for the DDD system, but I was discouraged from applying for help from DDD due to funding limitations

I've been seeking community based services for autism and complex trauma for years now to no avail. Seriously. It's been since 2019 or before, that I've been asking for trauma therapy. I received one referral but the counselor was a student and not a good fit. Our sessions lasted about 6 months and she pressured me into therapies that are generally not effective for people with autism. She expressed being unwilling to even hear that my apartment had roaches - how would she be able to hear and help with the really bad traumatic experiences I was in need of getting off my chest?

I've asked for accommodation regarding help with understanding the large amount of consent forms required by the Community based healthcare System. My request was denied. So, currently I am in limbo with no help. This has been going on for months. I've switched clinics in an attempt to find a provider of community based services that will provide appropriate services. I'm still searching and waiting. And in the interim I am

without support or the correct treatments and services for the conditions I actually have and not for the misdiagnosis I've been labeled with.

Because of being forceably detained against my will and assaulted in psychiatric hospitals and in the community, I have a difficult being in the community. I have yet to find a community based treatment team or system that isn't causing more harm than helping.

You asked

I am struggling to find something good about the System. I was for a while getting some help at a peer run organization. However, the last few times I attended - I actually felt worse by the end of the day than when it started.

I enrolled in Voc Rehab only to be chastised and disrespected by one of their counselors.

I struggle daily with symptoms, and lack of appropriate services and support. My health is not good and yet I get up each day and try to make the best of it. I feel beaten up, exhausted and discouraged by the end of most days. The System that's supposed to be helping people to heal is actually causing much harm and delaying and interfering with healing in the process

Regards,

Monti Worsham

3619 E Monterosa St Apt 110

Phoenix, AZ 85018

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because humans are of diversity in appearance and abilities, but not worth. Service goes two ways, and we are all of differing abilities and assets.

Regards,

Jennifer Becker

727 E 6th St

Tucson, AZ 85719

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a 33 year old son who is autistic and non verbal. It's hard for him to have friends because of this. He goes to a day program now and he has made so much progress. He never really wanted to participate in group activities. Now he does, he gets more involved than he ever did before. He enjoys learning new things/skills. His behavior has improved, he's learning how to deal with other people and how to handle certain situations. He loves to go on outings to the movies, bowling and the park.

When they were closed during Covid he had a very hard time keeping himself busy. There was only so much we could do without being able to go anywhere.

Without these programs he would be miserable. He looks forward to going and seeing his friends.

It's wonderful as a parent to see him smiling, learning and just enjoying life.

Regards,

Jo-Anne Gutsch

16760 W Bristol Ln

Surprise, AZ 85374

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my adult son on life support would not be with us today if it wasn't for him living at home. He is IDD, Blind, Hard of hearing, respiratory decency, CP, Oxygen, Tracheostomy, Gtube, and much more. He lived at a hospital, TMC, for one year. He was the first person home on a Ventilator in Tucson. The Doctors sent him home to die. They said 90 days at best and here he is 38 years later. He never would have survived an institution plus we don't have any for Ventilated people. So..Home and Community Living keeps people happy and alive.

Regards,

Darlene Lundergan

3921 W Wild Life Pl

Tucson, AZ 85745

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because they deserve the right to live their lives

Regards,

joyce carter

2929 E Broadway Rd Unit 27

Mesa, AZ 85204

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I care about people.

Regards,

Deidre Gotjen

13236 N 7th St

Phoenix, AZ 85022

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because,

People with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. Programs like Medicaid home and community-based services (HCBS) help make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.

Regards,

Shannon Sharifi

625 E Laguna Dr

Tempe, AZ 85282

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it trancends the prosperity of humanity when everyone works in unification.

Regards,

Aria Faamasino

1737 E Kramer St

Mesa, AZ 85203

Submitted on Friday, December 5, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son can live with me and not in a nursing home. He is able to live as independently as possible. He can enjoy and participate in community activities in our neighborhood. It's inclusion in the best sense of the word. He sings and can showcase his talent in our Christmas song along and Variety Show. Our friends and neighbors expect him to attend and sing Karaoke at the monthly events. He has made friends and is a valued member of our community where he enjoys monthly dances, the swimming pool, and the fitness room. His caregivers help him attend many of these activities and events. His neighbors speak to him when they see him walking in the neighborhood, and he's invited to their homes. Oh yes, Nathan is 43 years old; he is blind with intellectual and developmental disabilities. He also has Cerebral Palsy that has affected his mobility requiring him to use a walker and often, a wheelchair. And he is kind, funny and so very talented. He has performed The National Anthem for our local Special Olympics and other charitable organizations for individuals with disabilities. Ask yourselves this, would he be contributing to his community if he lived in a nursing home? Home and Community based services allow our family members with disabilities to thrive,

not just survive, and these supports help family caregivers to work, and have much needed respite to recharge. And an added benefit? Home and community based services costs less than a nursing home placement.

Regards,

Susan Singler

1134 W Calle Ronda

Sahuarita, AZ 85629

ARKANSAS

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

I live in a low income retirement building. Some are hud. I do get help with my rent.

I have a daughter but would be unable to live there. Her house is full of stairs. And there is no room.

I live alone in a studio, but have many neighbors and we watch out for each other. I do my own cooking and everything in my house is gluten free as I have celiac Disease. I dont have steps here. Ramps and a elevator.

I honestly cant imagine where you want me to go. I would be homeless.

I've worked for 53 years. 10 hr days 6 days week.

What sir did I spend my life paying into these programs for. For you to call it a entitlement and just make it disappear.

We want our independence. A quiet corner to have as our own.

I have many illness. CAD, Celiac Disease, PBC and CSVD.

There is medication i cant live without. (forPBC) Cooking gluten free is also expensive.

Not everyone has the ability to save for retirement. I was a single mom.

Such a horrible thing to be told we dont deserve to live. I believe this is what our new government is telling us. Because we cant live without help.

Regards,

Phyllis cox

2701 Aldersgate Rd

Little Rock, AR 72205

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because. I need Medicaid and on SSI . It's hard to make it , but I appreciate everything I get help with! My community I live in is small and great! Please continue to help ! Thank you

Regards,

Sheila Poarch

201 SE Railroad St

Redfield, AR 72132

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

I am a person living with autism, and Home and Community Based Services like the Community and Employment Supports (CES) Medicaid Waiver I receive in Arkansas has enabled me to maintain a life in the community and a job as a data analyst for almost 6 years, especially when paired with the Arkansas Workers with Disabilities Medicaid program which allows for a Medicaid Beneficiary to keep their Waivers as long as they would be qualified for SSI otherwise. This enables me to have a much higher quality of life than I would have if I did not have HCBS to enable me to stay supported and in the community. In turn, I am able to have employer provided health insurance and a Flexible Spending Account, both of which help with my increased medical costs which would either be born entirely by Medicaid (and thus the taxpayers) or go untreated altogether, possibly leading to more expensive problems down the road. Also, HCBS gives disability service providers a means to provide jobs for their employees, including the direct care staff that they employ, as well as business for the various suppliers and vendors that they engage with in the course of business. As for me, thanks to my HCBS supports, on February 29

2024, I was able to come to Washington DC to testify before the United States Senate Special Committee on Aging about people with disabilities thriving in the workplace (https://www.aging.senate.gov/hearings/all-means-all-empowering-people-with-disabilities-to-thrive-in-careers-and-the-workplace) , and before that I had never flown on an airline before. Afterwards, I managed to complete my Master's Degree in Health Informatics from Arkansas Tech University, get promoted to Data Analyst 2, become chair of the Arkansas State Rehabilitation Council (https://dws.arkansas.gov/ar-rehabilitation-services/state-rehabilitation-council/), and travel to Seattle in October 2024 for an NCSRC conference. None of this would be possible for me or others with disabilities without HCBS supports.

Regards,

Frank Hellmer

223 Summerwood Dr

Benton, AR 72019

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because without it I wouldn't have a place to live. I also wouldn't have access to healthcare or medicine. Medicaid helps me live with my chronic conditions and I don't think I would survive if access to it was not available. My daughter is my full time caregiver and can't work out of the home. We are working with Medicaid to help get her paid so I can remain at home and not have to go to a nursing home. Without programs like these I believe many people would end up on the streets or even dead. Access to these programs are crucial for older disabled people like me. Please continue to fund and support these programs.

Thank you

Regards,

Sharon Wozniak

7 Mt Gale Rd

Conway, AR 72034

CALIFORNIA

Submitted on Wednesday, November 19, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

Regards,

Ryan Duncanwood

478 Spire Point Dr

Redding, CA 96003

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps keep us united with many other people all wanting progress.

Regards,

Aidan Shanley

22 Acorn Ct

Walnut Creek, CA 94595

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me becausewe are social beings. We all flourish together.

Regards,

Joseph Gilbert

1037 N Rice Rd

Ojai, CA 93023

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because many of my friends are now older and need help.

Regards,

Ron Parsons

104 Claremont Ave

South San Francisco, CA 94080

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I support individuals with developmental disabilities for a living. I see their financial struggles and health struggles. They depend on Medicaid for medications and healthcare needs. It is a crucial part of their survival.

Regards,

Miko Baker

9411 Vintner Cir

Patterson, CA 95363

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because they are a part of the community and should be recognized and accepted as such.

Regards,

Willie Reed

5600 Imhoff Dr

Concord, CA 94520

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because with out I would be alone on the streets after my stroke

Regards,

Jason Langford

Crockett, CA 94525

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

My son is 23 years old he has Down Syndrome and Moyamoya - a rare arterial brain disease which he had 2 brain surgeries for in 2020. Without Medical we would of had to sell our house to have his health needs taken care of. Thanks to the amazing doctors and care he received he went on to go to a 4 year university inclusive program for students with intellectual disabilities. All of these things would not have been possible for him with out Medicaid funding. He is now done with college and is a thriving member of our community. He has a job, he volunteers in his spare time - at our hospital and hosting karaoke events for individuals with disabilities in our community. He has friends and a bright independent future ahead of him thanks to supports he receives. Without Medicaid HCBS he would be leading a very different life.

Regards,

Melissa Fitch

5070 Santa Susana Ave

Santa Barbara, CA 93111

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my adult son is disabled and on SSDI & Medicaid. He lives with me. I am an eldery woman, and I help him by providing a safe environment for him as well as much-needed emotional and practical support, and he helps me by assisting with chores and loving assistance as I am aging. We have a cooperative arrangement which upholds his stability and my stability. Without these services, he would not be able to afford his medications (severe mental illness) and help me with housing assistance. He does volunteer work half-time for the National Alliance on Mental Illness and this provides him with much purpose and a framework of structure where he assists others in their struggles with mental illnesses. He is saving lives by doing this work. Please do everything you can to prevent cuts in services as our very lives depend upon it. Thank you.

Regards,

Mary Rodgers

Modesto, CA 95350

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

I work with kids with Autism as a behavioral technician and we need to be there these clients and others.

Regards,

Carolyn Clark

27655 Calle Luna

Moreno Valley, CA 92555

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a developmental disability called “autism,” and I’m a transgender woman named Christina Hart. I live in California. I’m 34-years-old. My disability services at home in California pay for my ballet classes and guitar lessons. I’m

a musician and ballet dancer. Please don't take away my days at my ballet class and guitar lessons.

Please don't take away my rights to have a part-time job and do my paid hobbies that are my ballet classes and guitar lessons.

I create and sell my country and Hawaiian music albums and singles online to audiences in Australia and the United States on iTunes and YouTube using my TuneCore account. I promote my country and Hawaiian music albums and singles to audiences in Honolulu, Hawaii on Facebook for $20 for 5 days, so people in Honolulu, Hawaii can buy my country and Hawaiian music albums and singles on iTunes. Please don't take this away from me.

Please support disabled and LGBTQ+ people like me, our lives matter. Disabled and LGBTQ+ people are two special global communities of people, we can do anything and we can go anywhere, we have the power and the potential, we are strong and united people, we are self-advocates. I'm a self-advocate. We are doers and we are winners and we are the champions and the warriors.

Regards,

Christina Hart

2505 Esplanade Cir

Folsom, CA 95630

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Testimony for Senate Special Committee on Aging

The Life-or-Death Importance of Medicaid Home and Community-Based Services

From: Donna Ross Jones, CEO, Transition Music Corporation; Co-Founder, Special Needs Network

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How do programs like Medicaid HCBS impact your life? What would happen without them?

My son Nick is 27 years old. He has Level 3 autism and requires 24/7 supervision. Without Medicaid Home and Community-Based Services, he would not be living at home with

dignity, purpose, and connection to his community. He would be warehoused in an institution, and our family would have been financially destroyed decades ago.

This is not hypothetical. This is the reality for millions of American families.

The Math That Doesn't Work Without HCBS

When Nick was diagnosed at 24 months in 2000, I was told what every parent of a child with severe developmental disabilities hears: your child will need intensive, lifelong support. What they don't tell you is that without federal programs, the annual cost of that support can exceed $47,000-$70,000 per year - and institutional care costs even more, averaging over $47,000 annually compared to approximately $36,000 for community-based services.

No middle-class family can afford that. No working-class family can afford that. Without Medicaid HCBS programs, families face an impossible choice: bankruptcy or institutionalization.

I know this because I've lived it. Even with HCBS services, our family faced business collapse, financial devastation, and divorce under the strain of coordinating Nick's care. But those federal programs - the respite care, the day programs, the supported living services, the personal care attendants - those programs are what kept Nick in his community instead of locked away in a facility.

The Ripple Effect: How Cutting HCBS Destroys Economic Productivity

Here's what legislators need to understand about the economic cascade when HCBS programs are cut or inadequate:

Nick needs care.

Without HCBS day programs and support services, I must provide that care 24/7.

When I'm providing 24/7 care, I cannot work.

When I cannot work, I stop paying taxes.

When I stop paying taxes, I stop being a taxpayer and become someone who needs assistance.

Now instead of one person needing services, you have TWO people needing public support, PLUS the lost tax revenue from a productive worker forced out of the economy.

This isn't theoretical - the data is staggering:

According to research, parents of children with disabilities are three times more likely to make career sacrifices than parents of children without disabilities. Among parents with autistic children specifically, 55% report they have reduced work hours or quit their jobs entirely.

Caregivers of children with disabilities lose an average of $18,000 per year due to scaling back work hours or leaving jobs. Mothers of children with autism earn 56% less on average than mothers of children with no health limitations.

International studies show that the more severe a child's disability, the more likely the mother is to reduce work hours, earn less income, or stop working entirely.

Multiply this by hundreds of thousands of family caregivers across America. HCBS programs don't just help people with disabilities - they keep family caregivers in the workforce, paying taxes, contributing to the economy, and maintaining their own independence.

The false economy of cutting HCBS is staggering. You save $30,000 on day program funding and lose a $75,000 taxpayer. You eliminate a $40,000 respite care budget and create a $60,000 public assistance case. You defer HCBS services and pay triple for institutional care plus emergency room visits.

I run a company. I employ people. I pay taxes. I contribute to my community. I can only do this because HCBS services exist for Nick. Without them, I become another person dependent on public assistance, and my employees lose their jobs too.

This is not just about compassion - it's about basic economics.

What HCBS Actually Means in Real Life

Let me tell you what Medicaid HCBS looks like in practical terms:

It means Nick can participate in day programs where he learns life skills, socializes with peers, and contributes to his community through supported work activities. Without HCBS funding, these programs wouldn't exist or would be financially out of reach.

It means respite care that gives family caregivers the ability to work, to care for other children, to maintain their own health. Without HCBS, I couldn't have maintained my career or supported my neurotypical daughter Evyn. The entire family would have collapsed under the weight of 24/7 caregiving.

It means personal care attendants who are trained to support individuals with complex needs, preventing medical crises and emergency room visits that cost taxpayers far more than preventive community-based care.

It means supported living services that teach and maintain essential daily living skills, reducing long-term care costs and maximizing independence.

The Alternative Is Cruel and More Expensive

Here's what policymakers need to understand: institutional care for people like Nick costs taxpayers MORE than community-based services, while delivering objectively worse outcomes. According to recent data, institutional care averages over $47,000 annually per person, while HCBS averages approximately $36,000 - yet people in institutions:

- Experience higher rates of abuse and neglect

- Have shorter life expectancies

- Show increased psychiatric problems from isolation

- Lose skills they previously had

- Are separated from families and communities

Meanwhile, HCBS programs that keep people in their communities cost less while providing demonstrably better quality of life.

This Affects Millions, Not Thousands

Through my work with Special Needs Network and my blog "Autism Day by Day," which has reached over 3 million readers, I hear from families across America every single day. Their stories are identical to mine:

- Parents who can't work because there's no day program funding

- Families bankrupted by private-pay services when HCBS waitlists stretch years

- Young adults with disabilities aging out of school services and falling off a cliff into nothingness because adult HCBS services don't exist or are underfunded

- Siblings forced to sacrifice their own education and careers to provide unpaid care

- Parents in their 70s still providing 24/7 care because no community services exist for their adult children

The Urgency Is Now

I've testified before congressional committees. I've advocated at state and federal levels for over two decades. I've built organizations, created resources, and educated millions of families navigating these systems. And I'm telling you: the HCBS infrastructure is fragile.

States have massive waitlists for HCBS waiver programs - over 700,000 people across 38 states are waiting, with average wait times exceeding 5 years. Direct care workers are leaving the field because Medicaid reimbursement rates don't allow providers to pay living wages. Day programs are closing because they can't sustain operations on current funding levels.

If we don't strengthen and expand Medicaid HCBS:

1. **Families will be destroyed financially and emotionally**

2. **People with disabilities will lose the community integration they've fought for**

3. **The costly institutional system will expand again**

4. **Taxpayers will pay significantly more for worse outcomes**

5. **We will abandon the most vulnerable among us**

What Success Looks Like

Nick is 27. He lives with dignity. He participates in his community. He is known, valued, and supported in his neighborhood. He attends programs. He has relationships. He is not hidden away.

This is only possible because of Medicaid Home and Community-Based Services.

Multiply Nick by millions - because that's how many people with intellectual and developmental disabilities, older adults, and people with physical disabilities depend on these programs to live with the independence, dignity, and community connection that every human being deserves.

Programs like Medicaid HCBS are not "nice to have." They are the difference between dignity and warehousing, between community and isolation, between fiscal responsibility and financial catastrophe.

I urge the Senate Special Committee on Aging to not only protect these programs but to expand them, strengthen them, and ensure that every American who needs community-based support can access it.

Donna Ross Jones

Parent, Author

CEO, Transition Music Corporation

Co-Founder, Special Needs Network

Author, "Autism Day by Day" (blog, 3M+ readers)

Mother, Advocate, 25+ Years Navigating Disability ServicesCommunity living matters to me because

Regards,

Donna Ross-Jones

3570 Willowcrest Ave

Los Angeles, CA 91604

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I believe in diversity as a means to a richer public life. Everyone has their own unique talents to contribute and gifts to share.

Regards,

Kimberly Bostrom

1777 Clement Ave

Alameda, CA 94501

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I worked for many years for seniors people and with special needs. When you are sincerely, disabled, it is a sign of our humanity to help those who need it. A family that has a severely disabled member, cannot work if they need to take care of them every day. They are overwhelmed with expenses and difficulties, the least we could do is give them a hand as humans. Many people who sincerely need these services do not even know how to access them and do not take advantage of it. If we can provide in-home services, we can save money creating and sending them institutions. The institutions of the past were rather inhumane and very expensive, as I worked in one for many years. Giving honest disabled persons and families a hand at home, keeps family

caregivers able to contribute to society, whereas without the help they would not be able to.

Can you imagine what it is like to have a family member who has become a total dependent and you don't have the money to pay for help and you have to stay home to take care of them? In today's economy, you would never survive without a helping hand. We have always honored our humanity with compassion to those less fortunate. Do we really want to end our definition of humanity? To be or to have a family member who you love to be in such need of help is a heart broken burden by itself, why must we add to it? As we study our history, we have always noted that the sign of humanity is the helping hand, let us continue it. If we decide we cannot do that anymore, then we must open the doors to euthanasia because if we can help the people who can help themselves, we might as well not let them suffer. Please may we fight to maintain our humanity and treat people with equity, as we stated in the constitution. By giving a helping hand, we create equity which these people cannot have if they have the burden of being in need themselves or the burden of being the caregiver. Have we lost our hearts because it didn't happen to us and what would we do if it was us? I understand we have to skim off the people who take advantage of things, but the system is hard enough as is. To add to the difficulties creates a society of cruelty and a lack of equity. Just because you are disabled or a family member is disabled Have we come to decide that the disabled are worthless and don't deserve a roof over their head, healthcare, and food.

I have spent many years of my life, helping the aged population, due to illnesses, such as ALS, Huntington's disease, Parkinson's disease, strokes, cancer, and dementia, inside each of these people remains a human who has loved and given so much to society. How can we decide that they are worthless now or the family that is burdened with caring for them doesn't deserve help. I watched many people struggle to get the simplest of things presently from the government who deserved it 150%. Please don't take away any more benefits from those of us who are not as fortunate.

I am presently disabled after over a 30 year career and I purposely have not gone after disabled services because I understand that the system is so difficult, and overtaxed. Somehow I manage and I do without because it means so much to me that those who sincerely deeply cannot do anything for themselves can get the help they need. As a senior, I saved money for my retirement, but the cost of living has become so expensive that of course it is not enough money for the seniors in America anymore. The cost of housing has skyrocketed, leaving many seniors, not being able to afford a roof over her head never mind with a Disability. How can we throw our mothers and fathers and grandparents to the streets and then complain about them being there. Offering meals on wheels help for food

and help for a roof over our head and need healthcare seems to me to be a sign of a healthy society. People are living longer and with that it increases the chances of people not being able to care for themselves and needing help. Keep humanity alive, please. Continue the benefits and make it easier for those people who really need it. We cannot be a healthy humanity if we do not care about our fellow man.

PLEASE EXCUSE MY TYPOS, I HAVE A 70% LOSS OF USE OF MY HANDS IS VERY DIFFICULT FOR ME TO TYPE CORRECTLY AND UNFORTUNATELY USING THE MICROPHONE DOES NOT ALWAYS WORK CORRECTLY

Regards,

Lori Linberg

Palo Alto, CA 94301

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

living matters to me because

People with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. HCBS help make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.

Regards,

Nestor Ocano

3273 Via Zamora

Escondido, CA 92029

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have seen first hand how difficult life can be for those with health issues. The elderly are far more vulnerable to loneliness and despair because of isolation. Programs like Medicaid HCBS and Medicare help those in our communities who need the most help. Do not eliminate these programs.

Regards,

Sandina Mayberry

Knights Ferry, CA 95361

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my aging parents are going to need all the help and support they can get as they move to their 80s and taking away that support net is beyond cruel, evil, callous and sick!!!

Regards,

Amir Baum

7 Blue Heron Ln

Aliso Viejo, CA 92656

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

this sean nealy see try back in uour progms try work at mcrd

Regards,

sean nealy

5474 Encina Dr

San Diego, CA 92114

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

try back to program work at mcrd

Regards,

sean nealy

5474 Encina Dr

San Diego, CA 92114

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am part of these communities and want others around me to be happy, to cultivate healthy relationships!

Regards,

Jennifer Alonso

4126 Loma Riviera Ln

San Diego, CA 92110

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters because it truly allows marginalized and overlooked members of our community attain life goals, broaden their horizons and truly create belonging, friendships and often times find meaningful and productive positions.

Please take look at our model - we are an affordable, all disabled public housing community. We have been open for almost 5 years, serving 60 residents...extraordinarily successful. There need to be more opportunities for this type of success. www.villadevida.org

We cannot provide these services and housing without Medicaid and HCBS - this is the very definition of these services.

Regards,

Hunter Christian

12939 Pomerado Rd

Poway, CA 92064

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because everyone deserves a safe place to call home

Regards,

Stephanie Hart

2049 Sea Cove Ln

Costa Mesa, CA 92627

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we are a community...

Regards,

Derek Moss

1234 North St

Anderson, CA 96007

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it enriches everyone's life. Living with my brother has taught me so many important lessons and has given me great joy.

Regards,

Diamond Bell

1301 Indiana St

San Francisco, CA 94107

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Everyone deserves some type of medical care

Regards,

Cliff Atendido

1501 Ralston Ave Apt 105

Burlingame, CA 94010

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my parents can't support me

Regards,

Ryan Duncanwood

478 Spire Point Dr

Redding, CA 96003

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because continue services I need like keeping up affording health care and doctor visits, finishing up my college education and standing strong living independent afford housing in the future.

Regards,

Maria Rivera

851 Van Ness Ave Apt 816

Fresno, CA 93721

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me becauseI have a 17 year old son with special needs and when he becomes 18 even though an adult he will still need services to help him learn to manage his condition and lead his best life I an low income and if not for these services what would one do . Please keep the services disabled people need

Regards,

Angelica Gonzalez

174 Avon St

Pittsburg, CA 94565

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because of my working habits. It also makes me eat dinner at home

Regards,

James Cheng

14737 Live Oak Ln

Saratoga, CA 95070

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a 77 year old woman who has lives with a serious chronic illness for more than 23 years. It keeps me home bound, often bed bound. Yet my home is my haven, where I have constructed a life worth living. Without programs like Medicaid HCBS, people like me are shuttled into group homes that do not provide the right to happiness that our constitution should protect. Then life is not worth living. Please, so not relegate us to living hell at a time when we most need love and support!

Regards,

Barbara Kaplan

6450 Colton Blvd

Oakland, CA 94611

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm an intelligent, free thinking, self decisive with person centered goals who should be left to thrive and participate in a neighborhood /community of my choosing. I am a participant of several interest groups. Diversity modeling, songwriters and arts & media group for writers and authors.

If I didn't have the HCBS program I would have to limit my toileting and eating times to only twice a day. I would not have the ability to socialize, meet with my groups of interest or commit to my creative works. I would have no caregiver to be with me at night which is critical to my medical health sustainability.

These details may seem versatile in how to handle them. But it's truly about my human right to thrive in a country that permits me to be free.

Regards,

Nikki Diaz

300 Newland St Apt 9

Los Angeles, CA 90042

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. HCBS help make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.

I sit on the Board of New Horizons in North Hills, CA. This 70 year old organization has been providing critical services to this neurodiverse community and is highly successful in doing so!

If you cut funding these critical servies will diminish and then what?

Do not let this happen and do the right thing!

Regards,

Ron Burkhardt

1008 2nd St Apt 204

Santa Monica, CA 90403

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I work for the California Foundation for Independent Living Centers (CFILC), whose mission is to increase access and equal opportunity for people with disabilities by building the capacity of Independent Living Centers.

We serve over 26,000 individuals with disabilities, providing over 160,000 services to help them reach their goal of living independently.

Most of these individuals with disabilities are on Medicaid, so it is crucial that federal funding is maintained to accomodate their immediate care needs. Without this investment, our consumers could lose everything and become homeless or forced into institutional care facilities - both options that put more strain on scarce resources in their communities.

Regards,

Daniel Okenfuss

3900 Lennane Dr Ste 100

Sacramento, CA 95834

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because less fortunate people need care community cn prove, with proper funding

Regards,

Malcolm Moore

564 E Quincy Ave

Portola, CA 96122

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because s, loss of insurance coverage, and loss of home and community-based services for people with disabilities across the country. Thanks to the Lanterman Act's assertion of community-based services as a right for Californians with disabilities.

Regards,

Jonathan Santillan

4615 Clayton Rd

Concord, CA 94521

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my elderly mother receives these services and without them she wouldn't be able to make it. We need our representatives to stand up for people like my mother. She worked all her adult life teaching others and she deserves to live the best life for all her hard work.

Regards,

Afiya Wilkerson

2505 W 10th St

Antioch, CA 94509

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because there are so many people in my community who depend on this. Many of us cannot afford the costs of living without some additional support, because wages and laws have not adjusted for the increasing prices all around. Without these services, many people would be forced to pay out of pocket for healthcare. This might not even be possible for some individuals who can barely afford rent as it is, which would leave many people at risk of experiencing homelessness. Please protect my friends, family, and community by funding these programs and services.

Regards,

Cassidy Pedersen

2002 Villa Dr

Pittsburg, CA 94565

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

My home has two people living in it with disabilities. Myself which is from age and my granddaughter who has down syndrome and nonverbal. My granddaughter needs more help than I do. If she didn't have some of these services she wouldn't have bad or a chair. They have provided that and they have made it so that it's wonderful that she can grow with it. I really need some bars on my shower so I can get in and out of it. I do find it hard getting around the community and I do wish that they were more willing to help elderly than they are

Regards,

Evelyn Picnick

53265 Avenida Carranza

La Quinta, CA 92253

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am blind, deaf, and have balance challenges. I am a 66 year old woman with Usher’s Syndrome 2a. It is a genetic disease causing

blindness, deafness, and a loss of balance ability. I was born deaf and went legally blind at 58. I cannot live alone. I cannot see, hear, or walk unassisted. I worked until I went blind and now receive SSDI. I know President Trump wants me to just die, but I am actually a functioning member of society with assistance. I contribute to the economy, am active politically, volunteer with children groups, and am helping raise my granddaughters. The strong daughters I raised are a OT and a physician, both contributing members of society. Please continue to support assistance for the disabled. I actually don't need community living, but if I did not have my family, I certainly would. I would die without assistance from other people. I am extremely grateful for kindness and FUCK DJT!

Regards,

Linda Morgan

1608 Thurman Way

Folsom, CA 95630

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I know someone who has multiple sclerosis and can barely walk on his own. He lives in a low income retirement community, can't work so can't make income, and depends on SNAP and Medicaid. He barely gets much SNAP support, so I make sure I help out by making him home cooked meals at least once a week. He can't afford living in a nursing home and if he loses his housing he currently resides in he will be living on the streets.

Regards,

Francis Johnson

62 E 39th Ave Apt A

San Mateo, CA 94403

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I hate being isolated and depressed. I think it's a basic human right. Not going into the community is like being in prison. Would you want to be locked up?

Regards,

Crystal Joseph

2730 Winding Ln

Antioch, CA 94531

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Dear Congress,

My name is Mitzi and I am a direct support service worker who knows many people who receive Medicaid. Without the funding of Medicaid many of these people would simply not be able to live. The harsh truth is many individuals are born with life-altering disabilities through no fault of their own. Medicaid provides medical care for so many who cannot afford to pay for it on their own, they have disabilities that exclude them from being able to work and fund their own lives. I do not believe that they deserve to have this funding removed and genuinely believe we would see thousands of people die due to this action. Please keep an open mind and open heart and remember that caring for those who cannot care for themselves is the least we can do.

Regards,

Mitzi Diaz

5385 Concerto Cir

Concord, CA 94521

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because if I need to be seen by a medical doctor it is very important to have insurance without it is to costly for me to pay out of pocket. I am very

active in my program at Vistability. This will help me to continue participating in my program.

Regards,

Shirley Surney

1548 Ventura Dr

Pittsburg, CA 94565

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a disability called Cerebral Palsy, which is injury at birth. I have been lucky to have an independent life, but my disability puts me in a lot of pain, as a younger person, having the services of In Home Support Services made the difference in my ability to live in my own clean, sanitary home. Now that I am 82 years old, and unable to take care of myself in any way, the care I received from IHSS is the only thing that keeps me from being stuck in a bed somewhere and left to die. I'm just one of thousands of people to depend on these services.

Regards,

Karen Lobel

2510 Soquel Ave

Santa Cruz, CA 95062

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because without it I wouldn't have my home my health and my peace of mind. There are so many cuts to programs that make our lives better. It makes us feel stronger and happier and more productive

Regards,

Charlene Naumec

13808 Bordeaux St

Bakersfield, CA 93314

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

I am not disabled myself, but my older sister has mental health issues and lives in a community setting. It has helped her enormously, but cuts to these services and SNAP are likely to have a big negative impact on her life, and I am very concerned. These programs are enable her to be independent, which is very important to her.

Regards,

Dorothy North

2550 Dana St Apt 8H

Berkeley, CA 94704

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it creates a social support for seniors

Regards,

Patricia Goodson

12893 Island Cir

Clearlake Oaks, CA 95423

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I live in a senior community of over 300 people with disabilities and/or over 55. Collectively we all give and receive services from the wider community of Escondido. Many of us depend on services for survival or quality of life.

Regards,

Barbara Letsom

715 N Broadway

Escondido, CA 92025

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me

Regards,

STACIE CHARLEBOIS

701 Grandview Rd

Sebastopol, CA 95472

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have serious hearing issues 70% in left ear and 80% in right ear and will soon have to have cochlear implant in right ear. I am wearing hearing aids but they don't help much. My hearing loss is making driving dangerous for me. My hearing loss is creating problems with my vertigo and I have fallen 3x since June 2025. Fractured my right foot and had to wear a boot for a while this summer. I ain't Wonder Woman anymore!!!!

Regards,

Doris McDermott

28801 W Worcester Rd

Menifee, CA 92586

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, cynde Soto our vice president, who is totally disabled and dependent on MediCal for her life, just helped get $10,000 for grocery gift cards for older adults in our community for grocery gift cards. Even though totally disabled, cynde has connected us with other other

Organizations to benefit our community. She provided input in designing our program to include disabled seniors so all older adults would receive benefits. She is an amazing connector and advocate.

Regards,

Karen Reside

1150 E 4th St

Long Beach, CA 90802

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Our younger daughter, Ila, (now 11) has Cerebal Palsy. She is non-verbal and has learning delays, along with other medical conditions from the time of her birth. We discovered the Community-based program, VistAbility, just within the past year. And already, in less that 8 months, VistAbility's George Miller Center has proven to have a tremendous impact on her in terms of her social development, and access to life skill learning opportunities, and a sense of belonging that she does not receive in school. With programs like VistAbility, we see a long term path ahead for Ila, where she can continue to learn and grow with her peers, to continue to develop new skills reinforcing what she is taught in school, and ultimately contribute to society through work and education programs. We have already seen that if this program did not exist, Ila's social development, life skill learning, and access to her community would be severely negatively impacted, and her personal growth would be hindered as a result. We hope and pray that our Government and Congress continue to support Home and Community Based programs like VistAbility for the benefit of all of our citizens and community members like Ila.

Regards,

Aditya Joglekar

1929 Meadow Rd

Walnut Creek, CA 94595

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows my 49 year old son with Downs Syndrome to live a healthy, productive, fulfilling happy family life.

Regards,

Don Watte

2026 Winston Ct

Upland, CA 91784

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because as a care provider the residents in our home are treated with dignity and respect. They have the support the need to live quality lives like everyone else and they deserve that happiness. It saves the system to do things the right way instead of mass institutional settings that cause damage and harm to their well being.

Regards,

Danielle Rose

772 Jamacha Rd

El Cajon, CA 92019

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we need to there for each other, it is important in this technological age

Regards,

Janet Heinle

1047 Lincoln Blvd Apt 7

Santa Monica, CA 90403

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

November 21, 2025

To: United States Senate Special Committee on Aging Re: Hearing on the Importance of Community Living and Medicaid HCBS

Dear Chairman Casey, Ranking Member Braun, and Members of the Committee:

My name is Eric Anthony Devezin, and I am writing to you as a member of the In-Home Supportive Services (IHSS) Public Authority Advisory Committee in Riverside County, California. I am also a Doctor of Public Administration student focused on equitable community health policies.

I am submitting this testimony on behalf of the seniors, persons with disabilities, and care providers I represent to emphasize that Medicaid Home and Community-Based Services (HCBS)—known in our state as IHSS—are not just a benefit; they are a lifeline that upholds the civil rights of our most vulnerable citizens.

As an Advisory Board member, these programs impact my life by defining the health and stability of the community I serve. I work daily to bridge the gap between complex policy and the human beings who rely on it. Medicaid HCBS allows the people I represent to remain neighbors rather than becoming statistics in an institution.

In my work, I see that HCBS is the infrastructure of dignity. It allows an 85-year-old to age in the home they built, rather than a strange facility. It allows a person with a disability to pursue education and employment, contributing to our local economy. For me, living in a community that cares for its own—where independence is supported by policy—is fundamental to a functioning society.

If we did not have Medicaid HCBS/IHSS, the consequences would be catastrophic for my community:

1. Without the support of direct care workers to help with activities of daily living (eating, bathing, and paramedical care), thousands of seniors in my district would be forced into nursing homes. This is not only contrary to their wishes but is also significantly more expensive for the taxpayer than home-based care.

2. Without paid caregivers (many of whom are family members supported by these programs), working-age adults would have to leave the workforce to provide unpaid care, driving families into poverty and removing vital labor from the economy.

3. The removal of these services would signal that we value efficiency over humanity. It would strip our elders of their autonomy and sever their connection to the communities they helped build.

We cannot talk about "community living" without funding the workforce and the programs that make it possible. I urge Congress to protect and expand funding for Medicaid HCBS. We must ensure that direct care workers receive a living wage and that seniors have the right to choose where they live.

Thank you for your time and for elevating these essential stories.

Sincerely,

Eric A. Devezin, Member, IHSS Public Authority Advisory Committee: Riverside County, California.

Regards,

Eric Devezin

635 Villa Chaparral Rd

San Jacinto, CA 92583

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it is essentially important for everyone to have access to the living in their communities.

Regards,

Ryan Schrader

9623 Muroc St

Bellflower, CA 90706

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

People Need communities!

People Need connection!

People Need social services!

People need one another!

People ARE COMMUNITY

Regards,

Llll D

1000 Broadway

Oakland, CA 94607

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

If it weren't for Medicaid/Medi-Cal, I would be homeless or living in a shelter!! Thank God for Medicaid/Medi-Cal!!!

Regards,

Philip Lefcourt

811 E Washington Blvd

Pasadena, CA 91104

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, you lived with your own and that means much to the elderly people.

Regards,

Hamid Shiwoku

418 E Hardy St

Inglewood, CA 90301

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

I’m part of the community

Regards,

Ernesto Barajas

792 Delano St

San Lorenzo, CA 94580

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am still Able to participate and contribute to the overall well being if the community. We either live together in safety or the community is deprived of a valuable source of support for the others.

Regards,

Claire Jones

1000 N Lemoore Ave

Lemoore, CA 93245

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have worked with people with intellectual and developmental disabilities for over 20 years. This population wants to work and be a part of their community. Funding's that are cut to this population would be heartless. I agree cuts

should be made and there are many people utilizing the services that could work and do better for themselves, however this population is doing the best they can. The services that are provided through Medicade are essential for them to live and work and be apart of their communities. Please reconsider on cutting any funding that goes to the IDD community.

Regards,

Barbara Petsuch

5449 La Salle Way

Vallejo, CA 94591

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my brother has down syndrome and community-based services have had such an amazing impact on his life. He was lucky to be born in 1976 and by that time, society had realized incorporating people with disabilities in our lives is better than institutionalizing them. My brother is a thriving member of his community because of HCBS programs. If he did not have this support, I'm not sure what there is for him. He cannot live or work independently but he can thrive with community support based system. Without these programs my brother and many like him will suffer greatly. The cost of these community services benefits the entire community and should be borne by the entire community. If we go back to institutionalizing disabled people, it will be a dark time for our country (not to mention a waste of time and resources to do so).

Regards,

Kathleen Nichols

5530 E Big Sky Ln

Anaheim, CA 92807

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

THIS IS TRULY NEEDED Community living matters to me because for those that need HELP NOW

Regards,

Beverly Harris

2785 Whitney Dr

Fairfield, CA 94533

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we need the support.

Regards,

Cristina Sheppard

5388 Clayton Rd Apt T

Concord, CA 94521

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my niece has Downs and participates in an ARC program in Upstate NY.

Regards,

Deborah StJulien

4570 Kingspark Dr

San Jose, CA 95136

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because our son, Mike deserves emotional support of family and having his family involved to advocate for him. The family needs to ensure care plans are effective. Mike has grown up with his sisters and their friends and the rest of our

extended family. This has helped him grow as a human being. Mike enjoys interacting with his friends at his day program. He often helps those in wheelchairs making him feel useful. He also goes out in the community showing the public that those with developmental disabilities can do "normal" things.

Regards,

Christina Watte

2026 Winston Ct

Upland, CA 91784

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. Make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.

Regards,

Ken Donohew

4909 Tilos Way

Oceanside, CA 92056

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. Make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.

Regards,

Ken Donohew

4909 Tilos Way

Oceanside, CA 92056

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

CommuMy name is Bill Volkmann. During my birth, I had a traumatic brain injury which resulted in cerebral palsy. I never questioned myself or my abilities, I always thought about the difference I could make in the world. I was enrolled in a school for children with intellectual and developmental disabilities. My mother noticed that I was excelling in all subjects and started asking the town in New Jersey if I could go to public school. Although she was met with harsh negativity, my mother never gave up; she had the help of ARC and when the ADA was passed, she asked the school board again— but got the same answer. She sued the school and won because of the ADA laws in place. My mother prepared me as best as she could, but I had to walk through those doors of my brand new public school without the real knowledge of what to really expect. I proved my mother right and continued to achieve both academically and socially. I was proof that it was possible for more students with I/DD to attend public school. I moved to Florida before high school. Again, I found myself in a small catholic high school, the only one with a disability. However, I still achieved success in and out of school, learning to drive and partying like the rest of my peers. My father had been diagnosed with Multiple Sclerosis before I was born and it got worse with age, but seeing what I had accomplished made him not give up and live his life in the best way possible. Shortly after I graduated high school, he had stage 4 lung cancer and passed away within the year. A few months following my father's passing, my mother found out she had leukemia. All while I was struggling with my own health due to cerebral palsy. Isolation set in not because of my mom's health issues or my own, but the loss of my community, school was always a great social atmosphere for me but I had been absent more frequently. Five years later, I lost my mother but I got my health back. I moved to Houston, Texas, near my sister. I was a college student and living on my own, but I realized that if you have a college degree it couldn't guarantee a job. I tried to work, but nobody would hire me. I joined the local church, but people wouldn't talk to me much. I turned to my friends and family in Florida, I had my community again, but the healthcare wasn't good for my Cerebral Palsy. I moved back to New Jersey, where my other sister lived, for better healthcare. Again, I was met with the same thing as in Houston: Isolation. It came back even as I tried searching for employment and with the community. A few years later, my other sister moved to New Jersey from Texas because the education system would benefit her child with autism. He attended public school; being the first student with an intellectual and developmental disability allowed my nephew (and many others) to enjoy

his life. In 2021, my sister who came from Texas, fell ill and passed away a year later. I took care of my nephew while she went back to Houston in search of getting better healthcare. I had first-hand experience raising a teenager with autism. In 2022, I decided to follow my dream and move to San Diego. I didn't know anyone there, but I knew the weather and healthcare were much better there. I went to work volunteering at two foundations, even though this was different from other places I volunteered at in the past. San Diego was more accepting and saw me as Bill, not my disability. I was told about the regional center and I didn't know what to expect. In 2023, I became a client and was in awe of all the things I was offered. Their goal was to have everyone with an intellectual or developmental disability be like everyone else in California. For the first time in my life, I felt like I could have the life I always wanted; nobody had to worry about time or money and more importantly, I felt in control. I enrolled in the Self Determination Program that gave me the most choices. I am now able to live a healthy and safe life, going out when I want, day or night. Living where I want to live because of my needs, and knowing I will be taken care of with respect throughout my life. Since a significant amount of funding comes from Medicaid HCBS funding programs that I rely on for supportive living, which helps me live independently in my own home, and the people who enjoy the community and culture with me. I've had Supportive Employment for almost my whole adult life, and have dreamt of being a business owner. I'm determined to make it happen. I am grateful for all the therapeutic activities I get to partake in; I need to keep myself healthy, strong, and pain-free. This funding matters to me and many others. I don't want to go back into isolation; I want to help others with all kinds of disabilities be fully included in society. American society can benefit a great deal from a fully inclusive society regarding people with disabilities.

To me, this isn't a political, religious, or sociological-economic issue; it's a moral one. Disability doesn't see those issues; it affects everyone. It's also a human issue. How are we going to treat our fellow Americans who do their best every day? We need to stop kicking people down who are trying to make their lives better. The funds affect real people with their own hopes and dreams. As Americans, we should be cheering for them.

Regards,

William Volkmann

San Diego, CA 92103

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because We have people in our own family disabilities. What is to become if they don't get Medicaid and home and community-based services? They deserve help, and should get it, so they can lead a full and healthy life.

Regards,

Cheryl Demmon

161 Skyline Dr

Vallejo, CA 94591

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Thanks to Medicaid HCBS, I received respite support. It takes all my energy and time to take care of my daughter with CP, Epilepsy and some other diagnoses. Respite services restore my mental health, energy, and marriage.

Medicaid HCBS had also supported my family to pay for community activities for my daughter, like swimming and dancing. She would not have joined and met people in the community without this support.

Regards,

Patricia Jaimes

187 Agustin Narvaez St

San Jose, CA 95136

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it’s important for everyone to feel safe, secure and taken care of.

Regards,

Rosalie Prieto

9408 Cadbury Dr

Bakersfield, CA 93311

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because i can live in place where my piano is!

I don't know what i'd do without HCBS . . .

Regards,

Kim O’Reilly

5237 Nagle Ave

Los Angeles, CA 91401

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me.

Regards,

Erica Ponce

12984 Silver Creek St

Moorpark, CA 93021

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Thank you your support!

Regards,

Jerry otoole

450 S Seaward Ave

Ventura, CA 93003

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we all should live somewhere where others take care of one another and look out for us.

Regards,

Lionel Botvin

10823 Bloomfield St

North Hollywood, CA 91602

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because they bring joy and togetherness.

Regards,

Tracy Shortle

555 N Pine St

Orange, CA 92867

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because Helps keep me independent, allows me to live at home. I have access to health and social services. I can socialize with my friends and family. Without Medicaid HCBS, my long-term health care would be extremely expense, and I would be disconnected from my community. HCBS is the backbone of my life.

Regards,

IVY IACOPINI

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because Helps keep me independent, allows me to live at home. I have access to health and social services. I can socialize with my friends and family. Without Medicaid HCBS, my long-term health care would be extremely expense, and I would be disconnected from my community.

Regards,

SHERRI KRUG

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

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Community living matters to me because Helps keep me independent, allows me to live at home. I have access to health and social services. I can socialize with my friends and family. Without Medicaid HCBS, my long-term health care would be extremely expense, and I would be disconnected from my community. HCBS is the backbone of my life.

Regards,

WYATT BOLLINGER

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

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Helps keep me independent, allows me to live at home. I have access to health and social services. I can socialize with my friends and family. Without Medicaid HCBS, my long-term

health care would be extremely expense, and I would be disconnected from my community. HCBS is the backbone of my life.

Regards,

Jose Gonzalez

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters deeply to me because, as a direct service provider for adults with disabilities seeking employment, I witness firsthand the profound impact programs like Medicaid HCBS have on their lives. Every day, I see how our program provides not just training, but real opportunities for independence and self-sufficiency. Being able to gain employment gives these adults a sense of purpose, belonging, and the ability to contribute meaningfully to their communities. Without programs like this, many of these individuals would face isolation, limited opportunities, and a diminished sense of autonomy. These programs don't just support basic needs, they transform lives, fostering dignity, confidence, and hope.

Regards,

Laura Martinez

6506 Hansen Dr

Pleasanton, CA 94566

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because Helps keep me independent, allows me to live at home. I have access to health and social services. I can socialize with my friends and family. Without Medicaid HCBS, my long-term health care would be extremely expense, and I would be disconnected from my community. HCBS is the backbone of my life.

Regards,

MATTHEW BASSETT

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

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Regards,

Jose Gonzalez

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

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Regards,

MIKEL HALPERIN

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, it

helps keep me independent, allows me to live at home. I have access to health and social services. I can socialize with my friends and family. Without Medicaid HCBS, my long term health would be extremely expensive, and I would be disconnected from my community. HCBS is the backbone of my life.

Regards,

Sean Dunlap

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it's my job!!! i have been running a community Based program for 15 years. I have seen the improvements in the lives of my consumers by being in the community, working and socializing with not just their peers and coworkers with others. please make sure to keep programs like ours and support the people who support others!

Regards,

Megan Benando

1130 Burnett Ave

Concord, CA 94520

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Helps keep me independent, allows me to live at home. I have access to health and social services. I can socialize with my friends and family. Without Medicaid HCBS, my long-term health care would be extremely expense, and I would be disconnected from my community. HCBS is the backbone of my life.

Regards,

Jose Gonzalez

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because Community living matters to me because Helps keep me independent, allows me to live at home. I have access to health and social services. I can socialize with my friends and family. Without Medicaid HCBS, my long-term health care would be extremely expensive, and I would be disconnected from my community. HCBS is the backbone of my life.

Regards,

kathy lievore

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because Helps keep me independent, allows me to live at home. I have access to health and social services. I can socialize with my friends and family. Without Medicaid HCBS, my long-term health care would be extremely expensive, and I would be disconnected from my community. HCBS is the backbone of my life.

Regards,

Danielle Chinn

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Helps keep me independent, allows me to live at home. I have access to health and social services. I can socialize with my friends and family. Without Medicaid HCBS, my long-term health care would be extremely expense, and I would be disconnected from my community. HCBS is the backbone of my life.

Regards,

Jose Gonzalez

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because Helps keep me independent, allows me to live at home. I have access to health and social services. I can socialize with my friends and family. Without Medicaid HCBS, my long-term health care would be extremely expensive, and I would be disconnected from my community. HCBS is the backbone of my life.

Regards,

cherly sutter

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

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Helps keep me independent, allows me to live at home. I have access to health and social services. I can socialize with my friends and family. Without Medicaid HCBS, my long-term health care would be extremely expense, and I would be disconnected from my community. HCBS is the backbone of my life.

Regards,

Jose Gonzalez

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

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Regards,

Karla Marquez

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

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Regards,

Eva Wright

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

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5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

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Regards,

Marsha Kellogg

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

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Regards,

leslie gilmore

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, it helps me stay independent allows me to live at home. I can be social with my friends and family. Without Medicaid HCBS, my long-term health care would be extremely expensive and I would be disconnected from my community. HCBS is the backbone of my life.

Regards,

penny ghiggeri

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

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Regards,

dorrian collier

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

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Concord, CA 94520

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Regards,

stella mancbo

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, it helps me stay independent, allows me to be more social with my friends and family, allows me to live in my own home. Without Medicaid HCBS, my long-term health care would be very expensive, unaffordable and it will disconnect me from my community. Medicaid is my backbone, that helps keeps me stable and cover my bills.

Regards,

cindy tolentino

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Helps keep me independent, allows me to live at home. I have access to health and social services. I can socialize with my friends and family. Without Medicaid HCBS, my long-term

health care would be extremely expense, and I would be disconnected from my community. HCBS is the backbone of my life.

Regards,

Jose Gonzalez

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, it helps me live independently, have access to health and social services. I can see my friends and family. Without Medicaid HBCS, my long-term health care would be extremely expensive and unaffordable. I would become disconnected from my community which I do not want to happen. HCBS is the backbone of my life and I need it for stable living.

Regards,

john shillick

5600 Imhoff Dr

Concord, CA 94520

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because the people I serve as the Executive Director of Las Trampas School, Inc. in Lafayette, CA deserve an equal opportunity to live independently just like their peers without disabilities. I have worked with the intellectual and developmental disabilities (IDD) community for over 32 years and have seen how people, when allowed to be a member of the community, thrive more than those in institutional settings and, as a result, pose less of a cost on taxpayers.

If services are lost or diminished, the costs to taxpayers will only increase and create a crisis for people with disabilities and encroach on their rights.

Regards,

Daniel Hogue

129 Ventura St

Vallejo, CA 94590

Submitted on Tuesday, November 25, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I care.

Regards,

Jennifer Dokey

33181 Westchester Dr

Thousand Palms, CA 92276

Submitted on Tuesday, November 25, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I've worked as a DSP (Disability/Direct Service Provider) for over three decades, and I've seen firsthand the essential benefits that arise for people (with disabilities) who have opportunities to consistently be out in their communities while receiving the specialized support they require to live a full and vital life.

Regards,

Francis Kohler

1 Arkansas St

San Francisco, CA 94107

Submitted on Thursday, November 27, 2025

Dear Members of the Special Committee on Aging,

We are writing to ask that you protect Medicaid's Home and Community-Based Services. Art Explorers, Inc. is a creative arts program and progressive studio in Fort Bragg, California, serving developmentally disabled and neurodiverse artists. When you walk into Art Explorers, you are immediately surrounded by the creative hum of art and art-making. Eight or nine artists sit at tables deeply engaged in making drawings, paintings, lino-cuts, ceramics, and textile arts. Staff members move between tables setting up art-making supplies and offering support to the artists.

Forty-two artists attend Art Explorers one or more times per week. For several of the artists, Art Explorers has been a vital part of their lives since its founding twenty-five years ago. Our mission is to provide a fun, nurturing, non-judgmental, and artistically stimulating environment for creativity to thrive.

We facilitate connections between the studio artists and the wider arts community through a guest artist program, field trips, and the exhibition and sale of artwork. Artists feel pride and fulfillment when they see their work exhibited at venues in the community and especially when they earn income from sales of their artwork.

"Making art makes me feel good," says artist Frank Van Curen. "I love showing my work off and talking to people about my art!"

The front of the Art Explorers studio is a gallery and shop where the general public can come in and buy original artwork, and reproductions created on greeting cards, t-shirts and other textiles. Once a month, we participate in the town's "First Friday" art walk, hosting an opening that brings the artists together with the public.

Thirty years ago, people with developmental disabilities were isolated in institutions or kept at home and were not seen as vital members of society. One of the main objectives of Art Explorers is to provide a pathway to inclusion in the wider community to our artists. Art Explorers is the only creative arts program in Mendocino County that serves a neurodiverse population.

Proposed cuts to Medicaid will severely impact the artists who work at Art Explorers. Art Explorer's mission is made possible by essential services that support the dignity and independence of people with disabilities. If our artists lose the daily living assistance provided through Medicaid's Home and Community-Based Services, their independence and mobility will be diminished. Reduced access to medication and healthcare will have a

profoundly negative effect. Our program's funding by the Regional Center would likely be significantly reduced, meaning that we could serve fewer people.

"It would be hard to do things without the funding," says Van Curen. "I would just be bored at home. It makes me feel terrible to be stuck at home."

We don't want to go backward to a world where neurodiverse people are shut away from society and given second-class status. We want to continue to work for more integration of neurodiverse people in the community, with access to meaningful work, and an ability to express their unique perspectives.

Sincerely,

The Board of Directors of Art Explorers

Fort Bragg, California

Regards,

Maria Trombetta

235 W Fir St

Fort Bragg, CA 95437

COLORADO

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter is 14 years old and completely dependent on me and my care for her. She is wheelchair-bound, she has a cortical visual impairment, hearing loss, a severe developmental delay, no fine motor skills, no head control, osteoporosis, sleep apnea, is oxygen dependent, etc. Basically functions as a one to three month old infant. She is incredibly sweet, the cutest, and her smile could melt

Antarctica. The programs like HCBS are vital to her and myself. Being able to care for her not only provides a huge financial help, but also gives me an incredible peace of mind, because I know she's getting the proper care and comfort she needs. I do not have to guess or wonder who is doing or not doing a good job. She has eleven specialists that are in her care provider circle, and large monthly supply coverage, plus therapists and teachers. Her prognosis was 2 years. I firmly believe that she is 14 years old and thriving at her level because of the programs provided that have allowed me to give her the best care that I know how. She, and so many others deserve to be a part of the community. Everyone can teach us something, and gaining knowledge, understanding and new perspectives is vital to the growth of the human race.

Regards,

Casey Barrett

10861 Utica Ct

Westminster, CO 80031

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Do you know what it's like to wonder how you are going to feed your child? Care for your child? Pay hospital bills on top of everything else? Get denied by insurance?

We do. Kaydence is a 7 year old girl who is living with Canavan Disease. Canavan Disease is a progressive neurological disorder that will eventually end her life. But Kaydence is so much more than her diagnosis. She is a little girl who loves music and her family. She may never be able to walk, talk or care for herself but the Medicaid waiver programs in our state of Colorado have been able to give her the best quality of life.

With the CHCBS waiver all of our daughter's medical expenses are covered. This includes equipment, doctors visits, therapies and medication. This has been a huge weight lifted off of my shoulders. Our social worker told us that she will be covered for life, which is drastically different from the state we previously lived in.

When we lived in Texas, I constantly stressed on how I was going to afford caring for my child when primary insurance wouldn't even cover the food she needed to survive. Or how was I supposed to work full time when an in home health nurse is hard to come by and unreliable. When we moved to Colorado, that stress just lifted off and I was able to focus on other things like giving her the best quality of life and making family memories together.

Colorado has also instituted the IHSS program in conjunction with the CHCBS waiver. This program allows me to be her paid parent caregiver which eliminates the need for the state to find us a nurse and for the sometimes unreliable schedules of those nurses. I can now have a reliable and livable income by providing care for my daughter. Allowing her a safe and comfortable life. This has been a blessing for us and we hope it continues to be so.

Please reconsider making cuts to the community living programs that enable children like Kaydence to have the best quality of life.

Regards,

Kelsey French

4935 Sprangler Dr

Colorado Springs, CO 80922

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

We all deserve to live our life to the fullest with respect and dignity! Community living matters to me because we need each other! Enjoy the moment! We should not be sick or hungry!

Regards,

Belinda Lovins

11576 Monroe Way

Thornton, CO 80233

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because disability justice is justice for all.

Regards,

Gabriela Antao

400 Camino Dorado

Eagle, CO 81631

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because at I had a son at 19 years old and he was so sweet and perfect. At 15 months he swallowed some poison that severely damaged his kidneys and cost him his hearing. Without help from SSI and Medicaid I don't believe he would have survived. His situation was later made worse due to schizophrenia. Luckily it was treatable. He eventually received a kidney transplant which

Saved his life. He is now 57 years old and able to enjoy a happy life due to community programs and home care.

Regards,

Constance Slaten

Cortez, CO 81321

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because of I didn't have Medicaid I would not be able to afford going to the doctors. I need to go to specialist for my Lupus, my heart disease, and my Hashimoto disease. I would end up dead!!!

Regards,

Kayan Sherrer

2205 37th St

Evans, CO 80620

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because everyone needs different kinds of help. People looking out & helping each other is why we are on this planet.

Regards,

Dana Barela

601 Somerset Dr

Golden, CO 80401

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my family and friends and neighbors are part of community living.

Regards,

ronald brown

214 4th Ave

Longmont, CO 80501

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because all human life is sacred.

Regards,

Donald Bruestle

260 Lamar Ave

Pueblo, CO 81004

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my 42 year old son would probably be stuck in a nursing home or assisted living facility with elderly homebound people, and be unable to pursue his own interests. Such an inappropriate, inactive living environment would take a toll on his medical and emotional well being, depriving him of age-appropriate social interaction, work and volunteer activities, and most importantly life at home with his family.

We adopted our son as a toddler, promising him a loving forever family, not just a “fair weather” source of tangible and emotional support that could be taken away by a government “care” system when the going got rough. It did get rough, with disabling complications from surgery at age three. Thanks to Home and Community Based Medicaid programs, our son remains in his family home, has been working a few hours a week for the past 25 years, and maintains friendships that have endured since childhood. This supportive program complements the “natural supports” provided by family and community with professional home health services, mentorship, homemaker services and non-medical transportation among other things, at a fraction of the cost of living in a more institutional setting. Thank you for your continued support of these valuable programs!

Regards,

Debra Kovacs

24928 E Alder Dr

Aurora, CO 80016

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, Hi, as a parent of a non verbal, level 3 autistic son who isn't able to dress, bathe, eat, sleep bye himself, I can see him feeling shut in himself so to speak, as my heart breaks evrey day for him. As a parent caring for my son Patrick and advocating for our family daily I cannot make enough to support us and these programs make it possible, if he couldn't live at home he would very likely be misunderstood and institutionalized. His body would be alive but he would go downhill very quickly. These programs help him feel loved and helps him feel a sense of normalization within his community, being able to participate in empowering activities that increase his life skills and be out in the community. We are so grateful for these services because they make so so much difference in his quality of life, thank you

Regards,

Radhe Banks

12933 Ironstone Way

Parker, CO 80134

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

11-20-2025

Dear Congressman Hurd,

I am reaching out to you to share my story and tell you what independent living in the community and services like HCBS have meant to me. As a person with a disability, the ability to have an independent life is a great source of pride and accomplishment and is often considered to be a great milestone in the life of a disabled person. Services and supports through HCBS means that a person with a disability can have access to things like a Personal Emergency Response or medic alert system to keep them safe and give them access to 911 when needed. These services can also provide assistance by offering and allowing for things like Medicaid transportation to get around in the community so that we can get to and from work, doctor appointments, grocery shopping, etc. depending on if needs are medical or non-medical in nature. As someone who is both a person with a disability and a disability advocate and social worker, I do understand the vital support that HCBS can provide those who receive it.

Living independently can allow a person with a disability to pursue their goals and dreams that they still want to accomplish in their life. It allows them the autonomy to make their own decisions by living independently. Something they don't have if they are living in a care facility. HCBS can also provide assistance with personal care or home services for those who are not under the new CFC program. Many individuals who might find it hard to keep up with cleaning of their home can find homemaker services beneficial to assist them with cleaning the house.

I know that personally I still have a lot of things I want to do with my life and a lot of goals that I want to see accomplished as a disabled person, but I can't accomplish those things if my freedom is taken from me to do it. If President Trump wants to put people back to work, which I think is a great thing, then he should allow us to maintain services under Medicaid that can allow us to live freely within our community so that we can live, work, and contribute to society and support our community in general. Don't close off Medicaid

programs that can allow us to work in the community because you'll find that people with disabilities can be a very valued member of the workforce.

Medicaid Buy-in program for example allows individuals with disabilities to work so it doesn't make sense to cut that funding if Trump wants to put people back to work. It's also hard for people with disabilities to find jobs now because the funding for Division of Vocational Rehab just got cut also as I was reading in the local paper just the other day. It's making it harder for people with disabilities to exist because of funding cuts to programs like DVR and others so we can't really afford to lose HCBS too. Special education funding also needs to be saved so that students with disabilities can have fair and equal access to education. Without an education, people with disabilities will also struggle to find jobs and won't be able to fulfill the work requirements set in place by the President so they can keep Medicaid benefits. It won't do any good to have work requirements in place if you cut all the funding that allows people with disabilities to work so they can keep Medicaid. How will those requirements be fulfilled if you cut off our ways to live freely and get around in the community so that we can work and live? I ask that Congress would seriously consider saving a lot of the funding related to people with disabilities because trying to exist without it is going to be beyond difficult. Thank you for your time Congressman.

Regards,

Rochelle B

3098 Cedar Dr

Grand Junction, CO 81504

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, I'm the mother of 2 special needs adults and it is nearly impossible to get the care they especially with having to fight to prove thry are disabled something that they have had since they were babies.

Regards,

Jane Kimsey

Las Animas, CO 81054

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter wouldn't be getting out of the house and engaging with other people if it weren't for these programs. When covid came along, she stopped going out and then stopped wanting to go out. When we signed on with Respite Essentials, she blossomed and came out of her shell. This allows her to learn to engage with the community, work through the anxiety of going to new, unfamiliar places and being around other people, besides family. This program is crucial to her future and growth. She has done more new activities with community connector than she has with us, her parents. Cutting this program would be detrimental to her growth and her future to possibly learn to live in a group/host home or continue to engage with the community and her peers. Reconsider your position on this and how this will impact so many families who depend on the assistance and the needed respite from the continuous day to day struggles of raising a child/family member with different abilities.

Regards,

Dawn Courtney

1126 Sunflower Ave

Fruita, CO 81521

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it means my son and my sister can live at home with me, where they are surrounded by love, dignity, and safety. As their caregiver, I can make sure they have the support they need without losing the freedom and comfort of their own space — their home. They deserve a beautiful life filled with respect and compassion, and community living is what makes that possible. It keeps families together. It keeps hearts together.

Regards,

Thea Healey

7030 Wild Acres Ln Lot 2

Alamosa, CO 81101

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have three boys with special needs. They require daily care and multiple therapies. Taking this away would be detrimental to their health and their futures. Without the therapies and ABA they will not be able to learn the skills necessary for them to be productive members of society. I have also worked with disabled adults to help them find work and learn their jobs, this way they can be productive.

Regards,

Ashley Murray

211 Park Pl

Penrose, CO 81240

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows my son Jaxson to remain in my care and access services such as ABA therapy OT Speech Therapy. It provides services for him to gain access to the community and also helps with assistance in personal care tasks and other tasks where he struggles immensely unlike other normally developing 4 1/2 year olds. Community living allows Jaxson to work on his skills, such as socialization what is developmentally in behaviorally appropriate and learn to self regulate his emotions. Without His ces+ces services I fear Jaxson due to his behavioral problems will be institutionalized/ Jailed as an adult. Early intervention for him is crucial at this stage so that I can give him a fighting chance to be a functioning adult in a world that was not made for children like him. Choose our children their lives and futures depend on it!

Regards,

Brittny Tarango

9404 W 89th Cir

Westminster, CO 80021

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

My husband and I are full-time caregivers to our two sons. Both of our boys have the same rare gene mutation. Even though our oldest is 14 and our youngest is 6, their cognition will never grow beyond that of a six-month-old child. We feed them, lift them, change them, comfort them, advocate for them. Every moment of their lives depends on us being fully present.

Medicaid HCBS isn't just a program for our family—it's the reason we can keep our boys safe. It's what allows us to stay home and care for them, to get them to every therapy, every specialist, every appointment they need just to maintain the fragile health they have. It's what lets us help them experience their communities in the small but meaningful ways they can.

Without these supports, I honestly don't know what would happen to them. Our ability to give them even the most basic level of dignity, comfort, and quality of life would be shattered. These programs are the difference between surviving and suffering for our boys. They deserve to be cared for, fully and lovingly—and HCBS is what makes that possible.

Regards,

Amanda Sellen

1200 W 1st Ave

Broomfield, CO 80020

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have been a nursing assistant for almost twenty years working in hospice. My youngest son was not properly diagnosed until they were 18 years old with autism. I have always worked nights to care for my son during the day, and I am the only caregiver they have. Without Medicaid we would be homeless as we are already living paycheck to paycheck. My son could find no place to live on the $640 a month from disability if I was not here. Please keep our disabled citizens from suffering even more in these uncertain times.

Regards,

Tonja Weber

730 N Prospect St Apt A1

Colorado Springs, CO 80903

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

I have been a recipient of HCBS services for over 15 years. In the beginning, these services helped my mother who was ill care for me. At the time, she had Parkinson's and would not have been able to care for me full time without essential HCBS services.

When my mom became too ill to care for me, I moved from Tennessee to Colorado because Colorado allows for more Home Care services and less institutionalization of people with disabilities. If Colorado and HCBS services had not been available to me, I would have been forced to enter a nursing home at the far-too-young age of 29.

Instead, after moving to Colorado and with the assistance of HCBS services, I became a disability advocate where I protested for disability civil rights, including the right to live in one's community regardless of disability status.

I also worked part-time as a disability advocate at an independent living center for people with disabilities for four and a half years. While there, I had the honor of attending the National Center on Independent Living Conference. This was only made possible through HCBS.

After leaving that job, I became a part-time consultant of sorts for a pilot program emphasizing the importance of community-based services and how important it is for these programs to be simpler to navigate.

After leaving part-time paid work, I then worked limited hours as a volunteer for hospice and for a Colorado organization which has a food delivery program for individuals who are homebound.

Without the help of home and community-based services, instead of doing disability advocacy, I potentially would have been stuck in bed with no way to even use the bathroom or get food. Alternatively, I could have been housed in a nursing home at the vital age of 29.

Even if I had not had the desire to work and volunteer part-time, I deserve to live as independently as possible. I can't imagine the detrimental physical effects of being trapped

in bed unable to get my most basic needs met, nor do I care to imagine the detrimental mental health effects of being housed in a nursing home before my 30s.

The best way for me to live my life is by living in the community I love and being around the people I love - my Colorado friends, wonderful CNAs, and amazing disability advocates. I would never have met any of these people if it weren't for HCBS services.

Don't make it harder to access vital HCBS services. Let people with a disabilities keep our Independence in our communities. It is our human right.

Regards,

Stephanie Williams

8509 W 53rd Ave

Arvada, CO 80002

Submitted on Thursday, November 27, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

Regards,

Ekaterina Chernysheva

6838 S Ivy St

Englewood, CO 80112

Submitted on Thursday, December 4, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because the Medicaid home and community-based services (HCBS) helped me to get into housing after years of homelessness and difficulty establishing support or connections anywhere that I tried to live, no matter what I tried or did.

As an autistic/ADHD adult without family or friends to rely on for support, I was struggling for years due to lack of proper resources or support, and it would have a horrible impact on my life if these services and supports were not provided to me.

Without Medicaid home and community-based services (HCBS) I would not have housing for myself or my ESA. I would not have support in meeting my basic needs including housing, food, toiletries, support with transportation, support connecting in the community, and I would not be able to be a safe and comfortable member of our community.

Please continue to provide the Medicaid home and community-based services (HCBS). I rely on them for the ability to live a healthy and safe life.

I am certain that there are also countless other people who would also be homeless and unable to provide for their basic needs without these services and programs.

Thank you.

Regards,

Finneas Crystalite

4500 19th St Lot 585

Boulder, CO 80304

Submitted on Thursday, December 4, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my child deserves access to all resources due to her needs. She isn't an average child who can do things and she will be greatly impacted with the proposed changes. It's not fair to take from those who don't have access like the rest of us. The special needs should not be a target for cuts and loss of benefits.

Regards,

Kinzie Acosta

4610 Nautilus Peak Vw

Colorado Springs, CO 80924

Submitted on Friday, December 5, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because ,I believe that anyone with a child with disabilities should get all the help they need for their child, it's a full time job ,and there is no better person to take care of said child then their parent .

Regards,

Pamela Clute

1567 S Chelton Rd Apt D47

Colorado Springs, CO 80910

Submitted on Sunday, December 7, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

We depend on these Services and yet Colorado is taking them away.

The DD Waiver cuts and reductions go directly against the Olmstead decision Colorado Choice Transitions and Bill HB25-1017.

Bill HB25-1017 is mentioned in the 2025 news articles. April 2025.

Please scroll down to where I have the *** as that is the information that I was originally looking for - moving adults with disabilities out of nursing homes and Intermediate Care Facilities and into homes within the community.

Google AI:

"Colorado Choice Transitions (CCT) is a program created to help people with physical disabilities move from institutional settings, like nursing homes, to community-based living to comply with the Olmstead v. L.C. Supreme Court decision. This landmark ruling determined that unjustified segregation of people with disabilities is a form of discrimination under the Americans with Disabilities Act (ADA), and states must provide community-based alternatives when possible. The CCT program provides services and support to facilitate these transitions. "

The other articles and information I'm adding are what I came across while looking for this information because I couldn't remember the name.

This is just some of the information that is out there that shows that Colorado has been moving away from placing people with disabilities into nursing homes and facilities and placing them into homes within the community.

The recent Medicaid cuts and upcoming changes are putting all of this at risk - people with disabilities will end up back in nursing homes and facilities when the state closed many of those down years ago.

The information is out there.

Brief history of people with developmental disabilities in Colorado

https://www.slideshare.net/slideshow/a-brief-history-of-services-for-people-with-developmental-disabilities-in-colorado-and-a-glimpse-at-the-future/9323639

1974/1975

https://atlantiscommunity.org/about-us/history-of-atlantis-adapt/

1999

https://archive.ada.gov/olmstead/olmstead_about.htm

*** 2013 plan ***

https://hcpf.colorado.gov/sites/hcpf/files/Colorado%20Community%20Living%20Plan-July%202014.pdf

*** Colorado Choice Transitions ***

https://disabilitylawco.org/sites/default/files/uploads/Fact%20Sheet_CCT.pdf

*** https://hcpf.colorado.gov/cct-manual ***

"The HCPF manual states:

The CCT program will complement the Elderly, Blind, and Disabled Waiver, Persons with Brain Injury Waiver, Community Mental Health Supports Waiver, Persons with Developmental Disabilities Wavier, and Supported Living Services Waiver. The populations that will be transitioned through the program include: elderly adults aged 65 years or older residing in Health First Colorado nursing facilities, adults aged 18-64 with physical disabilities residing in Health First Colorado nursing facilities, adults aged 18 and older with developmental disabilities residing in Intermediate Care Facilities (ICFs) and Health First Colorado nursing facilities, and adults 65 years and older and individuals under 22 residing in institutions for mental disease (IMDs)."

2020

https://coloradosun.com/2020/02/05/colorado-medicaid-waiver-disabilities/

March 2022

https://courthousenews.com/

2023 court case

https://coloradonewsline.com/2023/10/04/adults-disabilities-segregated-colorado-nursing-homes/

April 2025

https://www.denver7.com/news/politics/colorado-bill-aims-to-codify-supreme-court-protections-for-people-with-disabilities

November 2025

https://www.theindependencecenter.org/blog/olmstead-and-the-fight-for-true-community-integration/

This is what I sent for the public comment form that I'm being told doesn't count because people aren't paying attention to it.

As far as the Staffed Home Option - none of the families who have been providing care for their own children with IRSS have ever heard of or even seen this as an available option. I specifically requested extra help and staff in my own home for my own son starting in December 2025 until March 2026 with multiple IDT meetings with The Resource Exchange and was given a bandaid solution to use 2-3 days of respite care per month, 10 hrs behavior line staff per week and Supported Community Connector which has completely fallen through because we cannot find a competent provider for that service.

There's also the fact that my son is too severe and needs 1:1 and he does not qualify to be a part of a day program, so that is not a part of his services either.

The Behavioral Line Staff is a horrible option that has nothing to do with behavioral intervention and is done without a BCBA or RBT and the fact that there's no access to true behavioral intervention with the DD Waiver is another area that is severely lacking.

The fact that the state wants to drastically cut pay rates to IRSS providers because of some made up staffed home rate is ridiculous. This option never came up once in our meetings where I requested extra help and Staff in my own home for my own son. The DD Waiver is supposed to be the most comprehensive waiver in Colorado and it has been severely

lacking in what families need compared to the SLS Waiver. There needs to be respite care provided under the waiver at an hourly rate. Please explain to me this back up care that you mentioned because I do not have that available through the host home agency I contract through. They have never mentioned anyone caring for my son so that I can attend my own doctors appointments, etc. I can only use them for their respite care option that's 24 hour increments. My son needs the residential services because he's very at risk for being placed outside the home itself. I cannot just switch to a different waiver because the DD Waiver is becoming the Least comprehensive waiver available.

And, you have the fact that the respite my son receives us in homes that have 1-2 clients.

It has become all about the money these people earn to care for at risk individuals in their homes because their daily notes and logs are unprofessional and lacking. They also severely lack the training and knowledge to deal with behavioral issues.

The state moved to have people with disabilities living within the community instead of being placed in nursing homes and institutions and yet everything that is being done at the state level is putting this at risk population at risk for being placed in nursing homes and institutions again. It is completely backwards.

This PETI is ridiculous too.

My son only has SSI and after the money goes to room and board, there's only $170 left and it sounds like it goes to PETI.

S Host Home is not a nursing home and this PETI is really going to hurt people with disabilities who are already struggling financial.

The only people who are not struggling with the DD Waiver and Host Home IRSS services are those who have more than one client in the home or who also provide the Supported Community Connector themselves.

This option for me providing Supported Community Connector for my own son is different when he only wants to be someplace with me for 15 minutes at a time.

The fact that we cannot find an appropriate provider since Covid precautions lifted should be an indication of how severely disabled my son is and I cannot even get a level 6 SIS because I refuse to lie like other parents that I see whose adult children can do independent activities that my son is not capable of doing.

There are many things that have been and are still lacking regarding the DD Waiver and its services and I'm tired of my son not being able to get what he actually needs became he is physically healthy, yet he is still seriously developmentally delayed.

Please note that my son was always IDD.

He started Early Intervention at age 1 in Ohio.

He was diagnosed with Classic Autism and Speech and Developmental Delays at 21 months old in Ohio.

I was born and raised in Colorado Springs and lived in Ohio while I was married to my children's father.

My son had access to OT, PT, Speech therapy, and his Early Intervention Specialist was using ABA concepts with him.

He was in the school system from preschool on and receiving a Waiver in Ohio as well.

He received SSI before age 3.

This is just part of my son's journey and he is still seriously developmentally and intellectually disabled.

We moved back to Colorado in 2004.

He received the CES Waiver in 2008 and I became a CNA and family caregiver in October 2008 - right before the Family Caregiver Act became state wide in November 2008.

My son received the DD Waiver at age 18 in 2014, when the DD Waiver was for 21+ because his Case Manager fought for the emergency placement for him because we were looking to place him outside the home.

I became his Host Home Provider in October 2015 after we got everything transferred over for him.

My son was able to remain in the home, but he is at high risk for being placed outside the home.

I cannot just get him the SLS Waiver because the DD Waiver is severely lacking in services even now - other parents have mentioned this to me.

My son is at risk for being institutionalized because of these changes.

Please also note that providers, parents, and case managers have pushed people to get on the DD Waiver because of the wait-list instead of having people research which waiver would actually be the most appropriate for the person becoming an adult.

They obviously were very ignorant about how the wait-list actually works because there is the emergency placements that come up and it's not first come first serve.

I am sorry that this information is not put together better for you all to read.

I have copy and pasted some things that I have written previously.

This is Heather Wilson and I thank you for reading this about my son, Brian Thomas.

I am his guardian, advocate, Host Home Provider, and I will continue to do what I can in a single mother and single income household where I cannot even get a Day Program or SCC services for my son and having an outside job or even a 2nd job is and has always been impossible for me.

I cannot even get into the level of care issues that the SIS, ISLA and other tools don't help concerning my son because he can walk, but he cannot do anything on his own.

I help him with everything..

I cannot even get a level 6 SIS for him and you have people who can ski on their own with supervision who receive a higher SIS just because of seizures and their parents lying about things.

It has really been frustrating fighting for the services that we have and we cannot even access providers for SCC and Day Program.

I must go attend to my son and have had many interruptions.

I hope this makes sense to you.

Thank you for your time.

Heather Wilson

hbk687@aol.com

Regards,

Heather Wilson

5102 Galley Rd # 103 # B

Colorado Springs, CO 80915

Submitted on Sunday, December 7, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

Colorado Medicaid benefits not only my life but greatly impacts its beneficiaries in my family. Especially my three year old Daughter; who is disabled and has special needs that her parent CNA Mother tends to.

Community-based services such as permanent supportive housing (PSH)

Is designed to help someone like myself who has been diagnosed with Non Hodgykins Lymphoma and have been hospitalized on multiple occasions. To have an opportunity to live independently despite my disabling condition and below middle class income status.

(The department of local affairs - division of housing)

With supportive services and clinical care to assist individuals in obtaining and retaining stable housing.

The State Colorado's 1115 wavier allows Medicaid to cover housing interventions through a partnership with the Colorado Department of Local Affairs (DOLA).

And as it is to my understanding covered services began implementation with a phased approach beginning in July 1, 2025, Health First Colorado (Colorado's Medicaid program) can reimburse Supportive Housing Providers (PT 89/208)

for the following services:

•Targeted case management for housing support

•Pre-Tenancy Support & Tenancy Sustaining Services

Home and Communtiy-Based Services Waivers

An HCBS waiver is an extra set set of Health First Colorado (Colorado's Medicaid program) benefits that you could qualify for in certain cases.

These benefits can help you remain in your home and community. HCBS Waivers have extra program rules and some programs may waitlists.

What would happen to me personally if I didn't have the Health First Colorado Medicaid program would hinder and delay my future aspirations.

However a greater negative consequence the communities within Colorado as a whole without Health First (Colorado Medicaid) and Home and Community-Based Services Waivers.

These Government benefits stipend and uplift the economy, the community, and its children of which there are many.

As a Father I care about the future and independence of my child and the future of the families I see everyday.

Regards,

Kaleb Williams

4834 Gatewood Dr

Colorado Springs, CO 80916

CONNECTICUT

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I was a teacher for more than thirty years! I taught children who experienced a variety of disabilities at a private school where no special services were available. We worked with the families to learn about what accommodations were needed, and we made them. I also observed the children closely to further support their needs. Every one of those children added in a positive way to the group, AND were pleasures to have with us! I had no special training, except for also being a mom, and I NEVER felt burdened in any way. These children are now well into adulthood, and I'm sure they have continued to contribute over the years. EVERY PERSON HAS VALUE!

Regards,

Hope Crescione

1873 Chapel St

New Haven, CT 06515

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because of life

Regards,

Daniel Coogan

6 Colonial Dr

Columbia, CT 06237

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son, who is 27, is able to live a fulfilling life in a community where he is able to work part-time, go on trips, take classes and attend various events such as Special Olympics and social get-togethers. My son lives in a garden apartment complex in an apartment that is rented by his community, Judith Creed Horizons for Achieving Independence. He shares the apartment with a wonderful roommate, and they are able to access all that the community has to offer, such as a movie theater, library and supermarket, with staff support as needed. Without the Medicaid HCBS program, my son would have to continue living with us until we were no longer able to care for him. Programs like Medicaid HCBS are essential for individuals like my son in order to live fulfilling lives. Thank you.

Regards,

Jerry Rothman

14 Harold Ave Apt 4

Greenwich, CT 06830

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because if the Essex Housing Authority hadn't found me an apartment I would have been homeless. Almost all my neighbors where in a similar situation. I learned that others shared very similar as myself. We continually share with each other in ways to make Life easier.

If I didn't have Medicare or Medicaid, I would have no healthcare. My SNAP benefits allow me to fairly eat well. My S.S. does not cover all my rent, bills & food.

Regards,

David Gephard

16 Main St Apt 20

Centerbrook, CT 06409

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

Community is necessary and helps to improve everyone's quality of life. In times of need or tragedy, communities come together, people help each other.

Regards,

Cheryl McCann

58 N Star Dr

Southington, CT 06489

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because of self-sufficiency.

Regards,

Melissa Meyer

7 Deepwood Rd

Simsbury, CT 06070

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it's an essential part of my life and living therein ' So make no mistakes to what your obligations are to the community at large!!!

Regards,

Clairence Pickens

62 Montville St Apt B

Hartford, CT 06120

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because solidarity

Regards,

Melissa Meyer

7 Deepwood Rd

Simsbury, CT 06070

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Commmunmyity living matters to me because I have a son with disability that lives in a companion home for the last 15 yrs

Regards,

Karla Kelly

55 Grove St Apt 43

Vernon Rockville, CT 06066

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps us all and to help those of us to help those in need. Getting involved and giving to your community helps pull it all together.

Regards,

Gerolynn Laukevicz

69 Dean Rd

New Milford, CT 06776

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because My parents are getting old.

Regards,

Kevin Walsh

155 Bishop Ln

Madison, CT 06443

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son with disabilities has a human right to belong as a member our society. A lot of people with disabilities can be active members of the community given a chance. Isn't that a lot better than having to be a drain on the system. Medicaid him into oblivion it's not satisfying for them or the people around them. My guess is you're not gonna even read this letter anyway?

Regards,

Lisa Considine

84 Palisade Ave

Trumbull, CT 06611

DISTRICT OF COLUMBIA

Submitted on Tuesday, December 2, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it is important.

Regards,

James Driver

4718 Bass Pl SE

Washington, DC 20019

DELAWARE

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because i care about the well being of others! Folks are frightened about loss of food, income, health insurance, education, voting rights, housing, safety, security, medical care, reproductive rights, life partner choices, and loss of democracy !!!!!!!!!!!!

Regards,

Amylynn Karnbach

17601 Coastal Hwy Unit 9

Lewes, DE 19958

FLORIDA

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we need to revive our government.

Regards,

Peter Bromer

15500 NE 9th Ave

North Miami Beach, FL 33162

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it protect vulnerable communities

Regards,

Renae VanWagner

1026 N B St

Lake Worth, FL 33460

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son would be would be completely alone in the world without his friends and support system.

Regards,

Jeannie Gauthier

6522 SW 112th Pl

Miami, FL 33173

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

I'm disabled and need surgery also a senior citizen who lives alone with service dog. I need help in my home after surgery so Medicaid is very important to me.

Regards,

Irma Romero

4228 Memory Ln

St. Cloud, FL 34769

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

It would be fantastic if since the cost of living and minimum wage were increased that the threshold for foodstamps be increased. Many of us make within $100 or so too much now to qualify for food stamps or food banks now and struggle to make it through 2 weeks let alone a month due to the drastic inflation over the last couple of years.

I know there are people that make much less than myself I feel for them at least they are getting different types of welfare assistance. Please don't take these services away they are essential to the disabled and elderly.

Regards,

Heidi Breen

368 SW Lacroix Ave

Port St. Lucie, FL 34953

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because medicaid helps me because I became disabled. A quarter of getting Medicare and medicaid helps more than Medicare without having to have co-pays or cash on hand which most times we don't, I don't make that money on disability so I can't afford much and being unsexate helps me pay my rent. Because I couldn't afford it. With the money that I make living in the community alone with my dog. I seldom get, but when I do. I try to help people in the community or donate money or food to the community.

And I tried to attend church as much as I can. But yes, I would probably die without medicaid.It's all I have.

Regards,

Sherri Collar

101Joey dr #1301

FL 32043

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

Regards,

Janice Andujar

2439 Hickory Oak Blvd

Orlando, FL 32817

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

My Community living matters to me because it offers affordability.

Please stop enabling:

1. the eviction of mobile home residents once their parks are sold

2. the rezoning of property from Mobile Home Park to Condo, residential or any other

3. Enabling the dissolution of existing Mobile Home Lease provisions such that market values for such existing lease property os not conveyed to current lessees, iow buy out at

value the potential buyer speculating on

Regards,

Andrew Puleo

161 Ponce De Leon Dr

Indialantic, FL 32903

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it gives my son a choice to live at home versus a group home. My son would not thrive in a group home and honestly wouldn't survive. The HCBS was a prayer answered. My son is allowed to move his life the way he wanted to not the way others want him to. We all deserve a choice.

Regards,

Tashia Holland

6406 Bay Cedar Ln

Bradenton, FL 34203

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Life is not fair, and never has been. But, to open your heart to the diversity of one’s community, to encourage acceptance and community support for people w/a wide range of challenges is exactly what our community is need!!

Regards,

Kathleen Eisenhauer

202 Spring Lake Blvd NW

Port Charlotte, FL 33952

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because with much hard work members of the Villages have established a 44 unit assisted living facility for disabled adult adults living in the Tri-County area. We attended a meeting about it and my 39-year-old son was very excited about the possibility of living semi independently with more opportunities for socialization.

Regards,

Colleen Camp

2515 Dividing Creek Path

The Villages, FL 32162

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because as a 19yrs with living with Autism,

Medicaid Home- and Community-Based Services (HCBS) allow me to remain safely in my home and maintain as much independence as possible. These services support me with daily activities that I cannot fully manage on my own due to my health needs, such as personal care, mobility assistance, and other essential tasks. HCBS also helps me stay stable, connected to my community, and able to focus on my health and recovery rather than worrying about how I will meet my basic needs.

Without HCBS, I would struggle to manage daily living activities safely and consistently. I would likely face significant health and safety risks at home, and I might eventually require hospitalization or placement in a nursing facility because I would not have the support needed to care for myself. Losing these services would also create emotional and financial stress, making it much harder to maintain my well-being and independence.

Isaiah J Rivera

Regards,

Isaiah Rivera

1954 Lake Waters Pl

Lutz, FL 33558

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because our daughter is 46 and needs 100% full time care. She has Downs Syndrome and doesn't have capability to make decisions or cook for herself. B/c of community based housing I can work and take care of myself and husband when needed. We have to be out of town a lot and no family for her to stay with so the housing provided for her has impacted greatly her life and ours too. Life was difficult before she received APD and receives money for housing. Please keep this intact and vote for things to benefit our mentally needy in our communities. Thank you.

Regards,

rhonda sherrer

1955 Stenerson St

Sumterville, FL 33585

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

I am a home health RN who provides private duty services for a young man in a very rural community with an aging grandmother as his primary caregiver. The young man sustained a spinal cord injury in a car accident when he was 3 years old and lost his mother and sibling in the accident. His family situation is uncomfortable and difficult. Where he is currently forced to live on a dirt road in a small rural town in Florida he has very minimal accessibility to society. Medicaid home based care services such as private duty nursing improve his quality of life with not only hands on caregiving, but also companionship and a connection to the outside world. His grand mother's health is failing and there is no one else willing to step up to take care of him. Without private duty nursing community based care, he would be forced to move to a Medicaid nursing home where as a young adult would likely truly struggle with the environment. Community based care keeps him at home in a comfortable environment where he can work on getting his GED and try his best to learn how to find his place in society.

Regards,

Nathaniel Ray

404 NW Church Ave

Micanopy, FL 32667

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a retired therapist and educator who has serviced so many via Medicaid. It is a lifeline , not a luxury.It is as essential as healthcare is to everyone. Inclusion and community living only helps people thrive and prosper. This is America and everyone deserves to do so. A. Ashford MA.

Regards,

Audrey Ashford

831 NW 58th St

Miami, FL 33127

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my adult autistic son deserves to live with independence, dignity and connection to his community. This would not be possible without the services that Medicaid HCBS provides.

Regards,

Toni Mascari-Luisi

1451 Scilly Cay Ln

Jupiter, FL 33458

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

I am advocating for my 24 year old granddaughter who has a cerebral palsy diagnosis Her life is enriched by programs provided by Medicaid. She especially enjoys the socialization with other disabled people. Her family's budget is helped by being providing with some of the products and services she needs that makes her life easier and more enjoyable. If she did not have these benefits, there whole family would suffer the losses.

Regards,

Doreen Roethler

32838 Timberwood Dr

Leesburg, FL 34748

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my adult son with autism needs his group home. He has become very happy and and well and making progress living among his peers. My husband and I know that if we pass away tomorrow, he will be taken care of... please make sure these individuals have a secure future with their funding. It's piece of mind for parents like us!

Regards,

Anne Bennett-Bready

12166 169th Ct N

Jupiter, FL 33478

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I 'm a companion

Regards,

Fonda James

1115 Bristol Dr

Cocoa, FL 32922

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it creates a sense of belonging and support. It allows people to share experiences, resources, and responsibilities, fostering cooperation and mutual respect. Living in a community helps build connections, reduces isolation, and encourages collective growth, making life richer and more meaningful for everyone involved.

Regards,

Derek Manzella

5364 NE 3rd Ter.

Fort Lauderdale, FL 33334

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

I'm about to turn 75. I have a fracture of L4-5 and T9 and stay active. I have two PT jobs on my feet all the time.

I suddenly got my sciatic problem back. Excessive standing I imagine.

I am single do not own a house, pay rents.

Some day I'd like a 1/1 so I can get my belongings out of my 10 x 10 storage unit.

I can't afford the prices for rent so I've been a too..ate for the past 9 years.

I am eligible for both Medicare and Medicaid thank goodness.

So I am aging but I do take care of myself as best I can.

Thank you.

Donna T

Regards,

Donna Thompson

75 Gulfstream Rd

Dania Beach, FL 33004

Submitted on Tuesday, November 25, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm a senior citizen with fibromyalgia. I was diagnosed in 2005. I lost my job, my apartment, my car and my 401K. I had to move in with my mother. I finally got Social Security after about two years. Receiving Medicaid saved me as it is doing now.

I live in Bradenton, Florida in a gated community. My father bought my mobile home for me about 9 years ago. This is a wonderful community with lots of amenities. I can't always participate but they are there for me.

If it wasn't for Medicare and Medicaid I'm not sure what I would be doing to survive. It pays for my prescriptions, doctors appointments and food. I know I couldn't afford my diabetes medications and all my other prescriptions. I would probably be living off one of my sisters.

Sincerely,

Susan Swiden

Regards,

Susan Swiden

2309 17th St Ct W

Bradenton, FL 34205

GEORGIA

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my main community is a senior apartment complex. The majority of the residents receive SNAP and Medicaid. Our rent is partially assisted by an income-based HUD program. I don't know what would happen to this community is those benefits were taken away.

Regards,

Joyce Lewis

Lithonia, GA 30058

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, as a retired RN/MSN (Masters in Community Nursing) - I has seen many programs to assist, train, re-orient (Veterans. like my self {18 months in Nam}).

So many that work with handicapped, mental, physical or mixed do so much good! These programs, run properly, create people who end up returning more good in occupation, citizenship then letting them become homeless or criminal!

Regards,

Bill Hals

4743 Tilly Mill Rd

Atlanta, GA 30360

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

As a young man who was diagnosed with autism at age 3, Ryan has many abilities yet many inabilities. Had he not been living in the community these past 31 years, he would certainly have much less abilities. He would not benefit from a group setting due to his communication difficulties. To prosper, he needed one on one instruction and the opportunity to make his own decisions.

Due to the amount of therapy, individual interactions, community involvement and individual freedom, he has grown into a very smart and funny young man.

Had he grown up in a group setting, he would not be the individual he is today but someone totally dependent on others for every need.

Regards,

Joan Griggs

3041 Habersham Cir

Covington, GA 30014

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because; I am a and have also been a person to service the community and others. Only because I've lived the life others are living. I'm a 38 year old Mother of 5 Blessings. I've been out of work for the past 3 years now. I'm injured and not able to really work. I have too many injuries. I'm under doctors care because of my injuries. I've been struggling all my Life. When I was able to work I had money to help others. Now I have nothing. Waiting on my social security taxes or something to give me financial relief while trying to heal. I know my Grammer my not be correct. I'm speaking for my whole Dekalb county area. I know we truly need help. I'm able to help you in return for helping me. Together we can offer knowledge and strength to rebuild communities properly. Also gain the people's trust.

Regards,

Delicia Smith

701 Boone Ct

Stone Mountain, GA 30088

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, our kiddo Isahiah, whom we adopted in 2020 at his age of 15, has Profound Autism and non verbal. He has the right to be in the community as a human being just like you and I. The HCBS helps humans like Isahiah and us the parents learn to live a somewhat normal life. In Isahiah's case he had had zero therapy when we adopted him. We came into this together no knowing what we didn't know about his severity and we started researching and making phone calls and was able to find an amazing BCBA that taught us how to teach him and how to handle behavioral situations. The school was a joke and did nothing for him. The community wasn't there for him the world around him wrote him off. I encourage you to keep HBCS for it is important in have an opportunity to have a life for these people.

Regards,

Brandon McGee

90 Corn Crib Ct

Newnan, GA 30263

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because7

Regards,

Monica Pierce

Smyrna, GA 30080

HAWAII

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I see hoe important it is to have housing for the participanst who live in our group home. Three of them used to be homeless which is not okay for people with IDD to live on the streets.

Regards,

suzette holtzman

3725 Kamehameha V Hwy

Kaunakakai, HI 96748

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we will all experience aging and face the many issues that come with it. Imagine it's you or a loved one needing assistance.

Regards,

David Mangel

15-1976 Beach Rd

Keaau, HI 96749

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because our adult son who has severe autism and OCD has benefited from home and community-based services that have taught his social and life skills. During the pandemic, our son was afraid to leave the home and was unable to care for himself, and was completely dependent on us, his parents. Now that he has regular home and community based services, he has gained the confidence and skills to be

able to go to medical and dental appointments, grocery shop using his SNAP benefits, and cook and clean for himself. He has learned to have conversations with others and has developed better self care habits including hygiene and exercise. As aging parents, we depend on outside help to assist our son, and we see how important these relationships and structure are to him.

Regards,

Karin Koga

67 - 1185 Mamalahoa Hwy

Waimea, HI 96743

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because to be alone is not a beneficial way to live.

Regards,

Kirk Tanaka

375 Aliiolani St

Makawao, HI 96768

IDAHO

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I feel that everyone deserves to be treated with respect. The handicapped and people of color are underrepresented and this needs to change. We need to ensure that all Americans need to have equity in our communities.

Regards,

Charles Morrison

Lewiston, ID 83501

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because without it at 74 I would need to bring my 50 year old son with intellectual disabilities back home to live with me. That would be so hard for both of us as we have spent the last 30 years making him as independent as possible. The hard truth is, I won't always be here and i want him to have a happy, safe life in community with people he loves and can depend on once I'm gone. In my situation, I lease the home he and his roommates live in. They pay the rent to the landlord and I help oversee the care and keeping of the home. Medicaid provides 24/7 care with staffing through a private agency called Renewed Horizons. Without this service we could not manage. Orher services for community based living we receive are in home occupational and physical therapy, community access programs for recreation and ongoing education. We have community case managers who help us find services we need and check in on staffing and living conditions for continued healthy environment.

My son, David has a life that is full and rich with friends and activities that makes such a difference in both of our lives. He has opportunities to volunteer and serve others and be a productive citizen. It certainly has not been easy in a system that says "NO" at almost every turn. It has been an uphill battle for our entire lives. If these community based services disappear the choice between an institution, nursing home or God knows what is pretty grim. Of course I would bring him home with me as long as I draw breath but what after I'm gone? Someone once asked me what was my ministry. I told them this...this is my ministry. For 50 years I have worked within the framework of a broken system that operates on the principle of waiting until the wheels fall off to fix or not fix the problem. Instead, why not look at ways to prevent the problems and set our loved ones up for success. Help us help our loved ones to stay in community and live happy, healthy lives.

Regards,

Roberta Knauth

34275 N Corbin St

Bayview, ID 83803

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my children live in this community. I live and wor in this community. My friends and family do too. When one of us is having a difficult time, we look out for one another in ways that make our lives better, people happier, and life better.

Regards,

Elizabeth McNeill

1204 S Euclid Ave

Boise, ID 83706

ILLINOIS

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it makes a huge difference to the people with disabilities and older adults in my community! Because of HCBS, our services keep folks active, independent, and connected to their communities.

Regards,

Andrea LeVasseur

4581 N Moody Ave

Chicago, IL 60630

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter has many of her resources in her community because of Medicaid! Never in a million years did I ever think I would have a child/young adult now with disabilities! Having Medicaid has been a blessing to me and my family!

Regards,

Lashawn Tate

18165 Sacramento Ave

Homewood, IL 60430

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am mother of a handicap child and a coach of Special Olympics of 36 handicap adults and now that I've had a multiple strokes I am now considered handicapped so this is very important to me in multiple reasons, these adults that have a special needs are very smart very patient and most important. They love very hard to everybody so for hearing people that say that they are not important is Ludacris you Congress should do everything that you could do to take care of these children. No matter what.

Regards,

Lisa Roche

11316 S Harlem Ave

Worth, IL 60482

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because some of my neighbors and myself are disabled and elderly. We all try to look out for each other. I love my neighbors and not being able to continue to live in my community would be devastating. However, we're just trying to make ends meet with some of us on fixed income. We thank God for the food pantry Free N' Indeed to get us by for the month. However, we need more assistance with housing, utilities, healthcare, taxes and food ! Please bring all of these things down and make it AFFORDABLE !

Regards,

Regina Jones

15139 Irving Ave

Dolton, IL 60419

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son, Leo lives in a CILA. If he did not have the funding for his CILA, I would not be able to work.

I have 2 sons with special needs, one of them is Leo. My ex-husband was abusive to me throughout the entire marriage. If I had know that the United States had group homes for people with developmental disabilities, I would have gotten out of the marriage many years before. This would have helped me tremendously because I gave up my job and my only income when Leo was born. I divorced my ex, but had to live with him in order to care for both of our son. I had no money. I am from Italy and I had no support. I was diagnosed with over 12 illnesses during the time I was with my ex and our kids. The reason why I was diagnosed with so many problems is because Leo would not let me sleep. He has a sleep problem and I had to keep him quiet at night so the others could sleep. During the day, the abuse from my ex and the non-stop work from the caring of our sons was so great that it almost killed me.

I am now working full time with CTF Illinois, but I have a lot of issue that are impacting my quality of life. I could have had a much better paying job by now and my own home and money in the bank and a good car. I have none of those things right now and it is very stressful. I have been renting a bedroom in people's home since 2012. Every time the living situation in the homes changes, I have to move out and find another bedroom to rent. All of this has taken a toll on my health

Regards,

Elena Storino

6760 181st St

Tinley Park, IL 60477

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

I'm writing this because people with families. Disabilities cannot survive without assistance. I am one of them. I am a single parent raising a 5-year-old and without snap and medicade I would not be able to make it. I also work. But with a rising cost of food and livonly the.

Rich can survive and nobody cares about the people that can't afford to eat and feed their children with light bills being 3 times higher than they used to be like a $1200 light bill for one month. How is the people supposed to pay these bills and feed their families?If there's no help , this is the most unhumane thing you guys have ever done. Does nobody value human life anymore? ?? I don't understand what's wrong with this government who poison us and lie to us.\nAll while using our taxes to pay their salaries. But yet here we all are in my family being one of them who can barely survive.\nBecause of what you're turning this country into. I know COVID was released on purpose, and then you gave the poison vaccine to the people who would listen to you guys and say it was safe.And now we find out it's not.I will never get a vaccine again in my life.Because of all the poisons , you put in them. And I promise who's ever in Congress government now, when election time comes again, they will not be in there.I promise , because the american people will vote them out as they should, it's time for newer and younger people who understand how it try to survive in a world where you've tripled. Everything property taxes food cost of living electric bills. I could go on and on, so I think you should all look to God. And\nPray for our country because you guys are all taking it away from us.And you don't care if we starve or live , as long as your pockets are getting full with our tax money.

Regards,

Tina Agnitsch

1945 Winery Rd

West Frankfort, IL 62896

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am very disabled.

Regards,

Michelle Billich

Chicago, IL 60614

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, I am a widow, I'm disabled, I don't drive, I rely heavily on my personal assistant. Without the support of everyone, who is in need of help and support. I would definitely hope that someone, who doesn't rely on these programs. Would never ever think of not supporting them. No matter what!

Regards,

Cherie BushongStarcevich

200 Sherwood Dr

Pekin, IL 61554

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have 2 kids with special needs and a mom(75 years old). I have to go to work my mom can't take care of her self she needs help with everything. I go for work and one of home worker come and help her with everything in the morning.

Regards,

Zaheen isnan

6046 W 129th Pl

Palos Heights, IL 60463

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it allowed my daughter with Intellectual and Developmental Disabilities to live at home in the community she grew up in. Colette lives at home with her mother and father providing her support for the last 31 years. Colette knows all of her neighbors and participates in all kinds of community activities and has

belonging in her community. Everyone knows Colette. If Colette didn't live with us at home she would be in a state institution. Colette needs assistance with all of her daily activities. She needs help to get out of bed in the morning. She needs assistance dressing and grooming. She needs assistance to cook and clean. She needs assistance in the community shopping, going for walks, etc. She is also very medically fragile and has had over 100 brain surgeries in her life. Despite this she loves being around people and socializing with them.

Being able to stay in the community that she knows and they know her gives Colette a wonderful quality of love. She is all about people and loves to be out and interacting with everyone. The cost form Colette's care would be close to $400,000 in an institution. The cost to keep her in her community is much much less. The cost to the state to keep her in her own community is closer to $25,000 per year. So living in the community for Colette is a win win situation for the state. It costs less and provides a much higher quality of life. She is happier, safer and living the life she chooses.

This is why HCBS matters!

Regards,

Gregory Walkington

4217 Lee St

Skokie, IL 60076

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

My disabled daughter is 38 years old and was born with a chromosome abnormality. She is developmentally impaired and is not able to live by herself. She is in a group home with ARC that is paid for by Medicaid and her SSI. If she did not have these services, we would have to bring her home to live with us until such time as we could no longer do so. Then what?!

Please vote to ensure her services continue so that families like ours are able to have our loved ones live as independently as they can.

Regards,

Susan Mekus

4220 8th 1/2 St

East Moline, IL 61244

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have worked with this community throughout my social work career. I've seen firsthand how important these programs are to our most vulnerable members of society, who desire to love with autonomy, dignity and respect. HCBS ensure that folks who desire to maintain their lives in our communities deserve to have this opportunity, as I know this is what most of us would choose if we were under the same circumstances. Please fight to save these programs!

Regards,

Joseph Naidnur

3031 W Larchmont Ln

Peoria, IL 61615

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

wife and I are 71 years old and parents of 2, 38 year old autistic non verbal men who attend adult day programs. Because they are non verbal and autistic, they need the outlet of organization provided adult day programs. They also have done amazingly well attending those programs 5 days per week while living in a group home with another 46 year old disabled, legally blind verbal man. They live in a home which I purchased but is staffed by a provider organization (Riverside Foundation)

The home located in a residential area near our community high school and they are transported by staff but also are part of the neighborhood.

Funding for their caregivers, transportation housing costs and food allows my wife and I to support our other 2 sons, their families and our 5 grandchildren along with our disabled sons like every other family in our community.

They need the support of the Federal government (the Medicaid Waiver) to live a successful life in the communities

Thank you

Paul & Maureen Koza

Regards,

Paul Koza

1508 N Sunnyview Rd

Libertyville, IL 60048

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have an adult disabled son who just recently moved into a CILA a few months ago. He has high support needs and caring for him and keeping up with his daily needs, activities and appointments became too much as we are aging. He deserves to be able to live and participate in the community as a young adult with dignity and respect. It has been our goal for him to be able to live independent of us before we get too old and/or pass away. This is an opportunity for him to grow, be around peers and have a team of people assist him with his needs and activities. This gives him a sense of pride and independence.

Regards,

Rhonda Payne

1507 Pine Trace Ct

University Park, IL 60484

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

I began mentoring a 12 year old boy in 2012; he lived in a “therapeutic” group home. I don’t know how many people realize this but neither DCFS not it’s contracted agencies provide

the services that claim to; if they do it is to a minimum degree. That said, this child was linked to DCFS from birth. He was adopted by his birth mother's cousin. His birth mother was serving 2-4 years in Cook County jail for, among other charges, failing to provide sufficient safety for her 5 year old son; while my mentee's biological father was sentenced to 75 years in the state penitentiary for murdering my mentee's 5 year old biological half brother. He has a sister who is one day less than one year older than my mentee; who became my virtual grandson. In terms of family, this child has a biological grandmother, an adoptive grandfather who was the most caring and nurturing of anyone around this boy (and his sister). His adoptive mother had a husband for about one year when she adopted the two kids. She had another husband when the kids were about 4 and 5. She also gave birth to two sons within that same time frame.

DCFS became more involved when he was 3 and started showing signs of ADHD. Backing up, the adoptive mother disciplined this child daily by physically beating him; he was often sent to bed without eating dinner; he was repeatedly physically and emotionally abused as well as emotionally neglected. His diagnoses include mild+/- cognitive impairment, learning disability unspecified and untreated; a speech impediment; 40% bilateral earring loss, ill-corrected club feet, severe trauma, cPTSD. (At age 18 he was walking with another boy from the same group home when the other boy pulled out a knife and stabbed my young man more than 23 times; he went into cardiac arrest three times and was on a ventilator for five days. A woman heard crying for help, the paramedics arrived in time to perform CPR).

At age three his "mother" began admitting him to psychiatric hospitals for purported aggressive behavior; most times the child denied any such feelings or behavior, but she insisted she wasn't comfortable taking him home. This scenario occurred 3-4 times a year. Often, she then refused to take him home giving the same excuse that she didn't feel comfortable. It not unusual for him to spend months "living" in the mental health unit of a hospital. He's almost twenty-two now. His grandmother, (adoptive) grandfather have cut him out of their lives saying he's too rambunctious and he's in legal trouble (he has never hurt anyone). I am the only adult who cares for him and about him and has a role in is life- a multi role; grandmother, advocate, emotional and financial support.

I don't how he would be able to live without the existing social services as feeble and minimal as they are. I am 75 years old, living on social security. I give to him all I can. He recently said to me, "we're like the two musketeers until one of us dies." I worry day and night how he will get.

Our government was born of and remains committed to the wealthy, landed white man. People like this kid will not be housed, will not eat or receive medical care without the help of the people-the government. Thank You

Regards,

Valerie Callozzo

4727 N Kilbourn Ave

Chicago, IL 60630

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because individualism is a set up for loneliness and other illnesses.

Regards,

Jose Nunez

2312 S 24th Ave

Broadview, IL 60155

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have worked with participants with disabilities for 18 plus years and also I have a grandson that is under the autism spectrum. HCBS are needed and essential in helping those to live, go to school and work.

Regards,

Debra Philips

2333 S 17th Ave

Broadview, IL 60155

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

ComPeople with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. HCBS help make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.munity living matters to me because

Regards,

Russ Ziegler

22 61st St

Downers Grove, IL 60516

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I Enjoy Good People.

Regards,

Daniel Manobianco

3607 W 68th St

Chicago, IL 60629

Submitted on Saturday, November 29, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because every citizen deserves the opportunity to a quality life. Living with disabilities has prevented me from driving, from retaining jobs, and now a bitch (Amy Hawkes at IDHS) has declared me no longer disabled. What is wrong with this world?!

Regards,

Elizabeth Wyman

1441 W Elmdale Ave Apt 3N

Chicago, IL 60660

Submitted on Monday, December 1, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we have a right to safer, affordable housing, and quality healthcare. Stigma and misinformation about disability suggests most who are diagnosed as disabled can't care for themselves or pose a threat to the norms of society. The disadvantages of poverty and both urban and rural myths is a culprit also. Many lose hope in treatment for disabilities due to it being inaccessible or for fear of being brainwashed by a medical system that treats people like guinea pigs. Those who have used resources and treatment to gain some independence such as finding housing, and maintaining medical regime can be what a community needs to prove false narratives wrong. It's important for not just those with disabilities to feel a part of their community but for everyone to feel they have just as much an opportunity as another with or without disability to live a healthy and safe life where they can thrive.

Regards,

Dawn Bedell

330 S Wells St

Chicago, IL 60606

Submitted on Thursday, December 4, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I was born with congenital heart defects and am disabled. Access to accessible housing, community and employment greatly improve an individual with disabilities quality of life.

Regards,

Elizabeth Grimwade

Chicago, IL 60625

Submitted on Thursday, December 4, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my adult son is supported in the community by a CILA and thriving in his current host home environment.

Regards,

Cheryl Kinsinger

1109 Westminster Dr

Washington, IL 61571

Submitted on Thursday, December 4, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a disabled parent and I depend on these services to keep getting medical care. Many disabled people of all ages from new born to elderly are in need of these services which have been threatened repeatedly by this president Trump and his administration in such a way that it's an insult to the progress that's been taking place in the lives of disabled people in the last few years, example disabled people just had gotten the rights to make above minimum wage right before this president decided to start cutting needed services for disabled children and young adults in our local schools as well as cutting funding for physical therapy that some of us rely on. Medicaid and Medicare,snap, WIC, IEP's are just as important or more so to the disabled and aging communities than to regular healthy people who don't have any impairments. To cut these programs for us in need is the same as undoing all the progress that's been made in the last 50 years towards making all lives better. Please keep helping us make further progress towards easing the struggles of the physical and mentally disabled so we can experience all that life has to offer at our own speed which may not be the same as someone who has no setbacks.

Regards,

Cathleen Hendrickson

407 S Springfield Ave

Rockford, IL 61102

INDIANA

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

because I've had 15 open heart surgerys I've been disapiled since I was born I can't work because of it

Regards,

Kenneth Cloud

29 Long Ln

North Manchester, IN 46962

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters because here is why I think that the Medicaid home and the community based services they offer like so many different Medicaid community based services programs and each of them are different that will definitely have a huge impact onto other peoples life's inside there own homes and also that would have a big effect there communities instead of the institutions I think that for the arc of Indiana for people have disabilities that do have Medicaid or don't have Medicaid now if they don't have all of the correct and specific documents it's small possibility chances that they may lose free access to there own critical services by leading them to a hard potential financial by the hardship and also a reduced for the quality for life

Regards,

Jake klemann

407 Ansley Ct

Indianapolis, IN 46234

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my 24-year-old son lives with Duchenne muscular dystrophy. The Health and Wellness waiver in the state of Indiana enabled him to get his college degree while living independently with professional caregivers provided by a combination of the waiver, Medicaid, and services provided by the state Vocational Rehabilitation Program. He is now starting a career as a writer and editor. His success would have been possible without HCBS services.

His father and I have also been able to maintain fulltime employment because we have HCBS for our son. Duchenne requires full-time care for all activities of daily living, and without help, one of us would have to quit our job to care for our son full-time. HCBS makes our entire life possible and we would be functionally, mentally, and emotionally lost without them.

Regards,

Mindy Cameron

Carmel, IN 46033

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Since becoming disabled at 36, my world, along with the community I had built have collapsed.

While on Medicaid I was able to schedule rides to appointments. I recently moved to private insurance due to concerns over funding cuts to Medicaid. Private insurance does not offer transportation assistance which has made scheduling and getting to appointments difficult.

I would love to be involved in my community, through volunteering or simply being able to attend community events. I'm not able to due to a lack of transportation. This has left me isolated for the past 4 years. I'm not able to see friends, make new friends or contribute to my community.

Before becoming a wheelchair user I worked at an art center, attended game nights with friends and helped manage community events. I was contributing and felt fulfilled. My life now is a stark contrast to the full life I had when I could walk with ease.

Programs supporting disabled people must be funded. There is so much the disabled community can offer to our surrounding communities. Our experiences are unique and

worthwhile to the greater good of all communities. We should not be hidden. Our differences must be embraced.

Able bodied individuals are only temporarily able bodied. This truth must be held in the forefront of policy making involving the disabled community. Whether through age or accident we will all eventually find ourselves as members of the disabled community. For this reason, these programs must be funded and expanded.

Regards,

Kat Kingsley

1814 S Scarlet Maple Ln

Elkhart, IN 46514

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because one day either myself, my family, my friends, or my neighbors will potentially become disabled. As we age, anything can happen to us or events unbeknownst to us will potentially occur. Those living with disabilities currently deserve a life of dignity as well, above all else. It gives them a sense of purpose and an ability to help the community in a way that makes them feel seen and heard. Please find the humanity in your hearts by continuing programs like Medicaid HCBS.

Regards,

Milena Lukic

2368 Black Gold Dr

Indianapolis, IN 46234

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm deaf and I'm unable to work and people like need more programs I can't afford to buy a new cellphone because I don't get very much on my disability and the connectivity program ended because you people in the government refused to funded it I don't know sign language I was never tought I'm 55

years old and people like need to be able to communicate I have inno caption call on my phone but that's not enough I keep telling people that I'm deaf and the only other way is through va text messages or emails but a lot of places refuse to honor my request for thoes types of communication . I need a new cellphone but like I said I can't afford to buy one I really wished you people would help instead of taking photo ops all the time and I wished you people would listen to your Constituents and help us thank you and God bless you all

Regards,

Kristie pate

Anderson, IN 46017

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it gives my son the freedom to be in his own home environment with his family and friends. And it also gives him the ability to be taught how to Rand live independently.

Regards,

Tawonia Taylor

1451 N Belleview Pl

Indianapolis, IN 46222

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, My Adult Son Has Autism, Epilepsy, Mild CP, & Learning challenges. He is an amazing Human Being who thrives in a supportive Environment. Being able to get services in the Home, where a Therapist works with Him in the Community has enriched His life tremendously. We put in the work with Him for over 33 years, with the support of phenomenal therapists, & He is coming to a point, we will be looking for Housing with another person or two, and Support Staff. Without the services that are currently available, He would have never reached the stage He is now at. We will forever be grateful! We have goals for Him, that He is starting to get excited about, as we

talk it up daily. He LOVES cats, and desires to take care of Cats at an animal shelter. We call it “Socializing” Cats, while expanding His Horizons.

I have been Disabled for several years and have benefitted from services that have kept me in my home, which I am extremely thankful for.

my Mother has Alzheimer’s Disease, and My Father was able to keep her home with Him with the help of in home services, until two years ago, when she could no longer walk & He physically could not care for her any longer during the hours the homecare staff wasn’t there. So, he had to place her in a home.

Without these services, my Son wouldn’t be able to talk, make decisions, control his behaviors, He wouldn’t have hopes or dreams or a future. Because of these services, you can have a conversation with him, he would freeze rather than decide, he would have outbursts when not with direct family. The opportunity to be with different people in different environments would not gave happened without the programs made available to Him through Waiver services. These opportunities have helped him grow as a person.

For myself, HCBS has allowed me to stay home, have assistance that has prevented falls & injuries, kept me in a place of being kept part of Society instead of closeted away somewhere to shrivel up and die. We live at a time where Extended care facilities, are short staffed regularly, the turn over is constant due to burn out, because of poor staffing. Poor staffing, is a problem, I have no clue how we as a society can fix. But, I have no doubt, it can be done with the right incentives. Whenever Possible, I think people should always be able to stay in their own homes. Because of the one on one care, burnout is seldom an issue.

When I worked the field years ago, I did both, Residential care and Home care. I loved both. But, not everyone is cut out for both. Some do better with one over the other and that’s great. I love that HCBS gives people a choice to have what’s best for each individual.

My point being, Direct Care Workers, Disability Service Providers, & all Organizations that serve persons with Disabilities & the Elderly are essential parts of providing persons with a good quality of life. In home is best whenever possible.

Thank you!

Regards,

Terry Jordan

7814 Sault Sainte Marie Dr

Indianapolis, IN 46227

777

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son has an intellectual disability. He brings so much to every aspect of the community he is part of and he will need support to live independently in his community. The home and community based services he utilizes through the waiver give him the opportunity to master skills we all need to live in our communities.

Regards,

Mendi Cooley

16526 Connolly Dr

Westfield, IN 46074

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

This is my story.

My name is Christina, and I am a resident of Perry Township in Indianapolis. I worked for the City of Indianapolis for 20 years until my disability, a form of Muscular Dystrophy, made it impossible for me to continue working. Since 2003, I have relied on Medicaid's Home and Community-Based Services (HCBS) waiver to live independently and remain integrated in my community.

Because of HCBS, I receive attendant care during the weekdays while my husband works. On evenings and weekends, he provides support. Without HCBS, my husband would be forced to leave his job to care for me full-time. This would push us below the poverty level and likely into homelessness. HCBS allows us to maintain financial stability, dignity, and the ability to participate fully in community life.

With the help of my aides, I am able to enjoy everyday freedoms—such as going out to restaurants with my husband. We are food enthusiasts, and dining out is one of the ways we connect with our community. These experiences are not luxuries; they are part of living a full life, exercising my civil rights, and being included as an equal member of society.

The Americans with Disabilities Act (ADA) guarantees that individuals with disabilities have the right to live and participate in the community without discrimination.

Research shows HCBS improves quality of life, reduces reliance on costly institutional care, and supports family caregivers by allowing them to remain in the workforce.

HCBS is not just a program—it is a lifeline. It ensures that people like me can live with dignity, independence, and inclusion. Reducing or eliminating these services would not only harm my health and well-being but also violate the principles of civil rights and community integration established under federal law.

Regards,

Christina Trimnell

2800 E Loretta Dr

Indianapolis, IN 46227

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because both my mother and my sister were spared being in lockdown facilities because of the opportunities provided due to the funding. My mother shared a house in a real neighborhood with an older lady. Mom had schitsophrenia so she needed to have support. She needed someone to make sure she took her medicine and got to her Dr appointments. The older lady needed round the clock support in case she fell or needed medical help. There was someone there at all times but they didn't live in an institutional situation. They had a real house and nice yard. They were able to go to store or out to eat. They were able to get their hair done. They never missed a Dr appointment because there was someone there to keep track of them and get them there. If there wasn't funding for this mom would probably have been put in a lockdown mental facility and the other lady would have been wasting away, waiting to die in a nursing home. As for my sister, she has a psychotic break and was admitted to a lockdown facility for many months. When she stabilized she was transferred to a group home where she was able to still get the supervision, and therapy she still needed while she was able to become part of society again. While she was there she received help with getting her disability. Now she lives in her own apartment instead of becoming another homeless statistic.

So as you can see I firmly believe that these programs were instrumental in providing a quality of life for them that was much better than what they would have had without them.

Regards,

Mary Dooley

834 W Blaine Ave

Elkhart, IN 46516

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because a nursing home would kill me. I have Lupus and Epilepsy and I have a low monocyte count which means I am immune compromised. Staying at home keeps me safe from getting the myriad of infections and viruses that circulate in a nursing home. I am also allergic to perfume, Febreeze and any scented cleaning product and perfumes trigger my Epilepsy. Spending 20 minutes visiting a nursing home that is filled with perfumed cleaning sprays is enough to make me have seizures. When I used to visit my Grandmother at her nursing home I would have to wear a carbon filter face mask and stay for a short time. I survived well in my home, in a germ free and unscented environment, living in a nursing home would probably kill me within a month. I am grateful to stay out of one and stay in my home. If you cut off Medicare and SSD and forced me into a scented and germ filled nursing home I would die quickly.

Regards,

Anna Robertson

382 E 650 S

La Porte, IN 46350

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it has made a huge positive impact for my nephew who has Muscular Dystrophy.

Regards,

Susan Smith-Beard

7008 Willow Pond Dr

Noblesville, IN 46062

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because there's no help for those who are in between jobs. My wife lost her job because they asked her to do something illegal. She tried to do another job but couldn't because of her disability and because of that she lost her chance at foodstamps and unemployment. She used to be disabled and really should be still but she wants to work. We have the foster children, legal gaurdian of four an older disabled son. We adopted seven children and they are all raised. Now we are raising seven more. It was prophesied to us at church that God would fill our house and God did. Including a girl we took in at age 15 when her mother passed away. A total of 15 children. This didn't include the children we helped with their children. I personally believe that there should be more help but more consequences for people who abuse the system. Like selling foodstamps, etc. My mother now lives with us because she can't enough help to live on her own.

Regards,

Gary Brown

Huntington, IN 46750

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because4 job skills

Regards,

summmerstar brewer

1428 Jeanette Ave

Evansville, IN 47714

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I love interacting with people after having MS for 22 years. I go to church to fellowship with others and donate

. I also like to know people who are around my grandchildren.

Regards,

Michele combs

9980 E 100 N

Knox, IN 46534

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because as a disabled person (learning disabled) at this time in Indianapolis there aren't any resources available to me. I can't drive, I'm too disabled to depend on public transportation so, for me I'm stranded. Indianapolis is a large city and growing daily should have better resources for the disabled and I'm elderly also. I can't get around because my income is come from social security disability. Barely enough to servive on. I'm very lonely and isolated because there is no service for me.

Regards,

William Baggett

6380 Crimson Cir W Dr

Indianapolis, IN 46227

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I personally am a parent of an Amazing 30 year old son with Autism & multiple other disabilities. We depend on these services every week! He is learning how to become more independent in doing various necessary life skills out in our community & has even started working this last July! Non of this would have been possible without these services! As my husband and I age, it is a huge goal of

ours to try to help our son become more independent! Taking these services away from people like him would be horrible! These disabled individuals deserve the right to become all they desire & deserve to be! They can & will be valuable citizens with just a little additional help to learn how! Thank you!

Regards,

Kristina Faulds

2906 W 11th St

Anderson, IN 46011

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

We need to come together help one another I liked to see more programs for people like and many other citizens with disabilities

Regards,

Sherry Burden

1010 W 3rd St Apt 6

Grandview, IN 47615

Submitted on Sunday, November 30, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my twenty-three Autistic son receives Medicaid Waiver Services.

My son has a Easterseals Crossroads job coach, a IPMG case manager, a therapist and recreational therapist.

The Medicaid Waiver Services are necessary to assist and support my son with daily work duties at Community North Hospital, a licensed therapist, a job coach, CICOA Freedom Transportation program and his IPMG case manager. As of November 23rd my son has lived in his own apartment for two years.

Regards,

Precious Johnson

1638 Ingram St

Indianapolis, IN 46218

IOWA

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because every life matters

Regards,

Mary Doubrava

Urbandale, IA 50322

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because anyone can be injured or get a disease that leaves them disabled. This is especially true with the massive healthcare cuts starting next year, leaving Americans without treatment for preventable illnesses or adequate care for injuries. Older Americans are at greater risk of disability and we all get older. Prolife has to apply to human beings in one of the richest countries in the world.

Regards,

Sharon Moss

2175 Kountry Ln SE Apt 11

Iowa City, IA 52240

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son who is Autistic & mentally challenged gets to do things & go places with the group. . MEdicaid has helped keep him healthy & nursed him back to health when he had COVID. He might not have survived if not for Medicaid, he lost 35 pounds. Keeping him busy bowling, dancing, going for a boat ride. keeping him busy keeps him out of trouble.

Regards,

Evelyn Noel

14507 25th Ave

Onslow, IA 52321

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows my husband and me to work without worries. We have a 26 year girl, at home, with multiple medical issues and having nursing care gives us reassurance that she will be taken care in the comfort and safety of our home.

Regards,

Jeanne Clapsaddle-Janssen

2528 Covey Ct

Cedar Falls, IA 50613

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

I am writing to ask for your support for Medicaid Home and Community Bases Services (HCBS)

My son is a 35 year old diagnosed as being on the autism spectrum with an IQ of below 30. He has a limited ability to understand speech and will never be able to work.

Since 2019, he has lived in a group home supported by Medicaid HCBS. This has been a godsend for us as well as a huge positive for him. The love and caring he receives has

enriched his life immensely. Losing this support would be devastating to him. He would also have to be sent to a nursing home with a cost to the government far exceeding what HCBS costs.

In addition, my wife and I are in our late 70's and cannot provide the 24/7 care and supervision he requires to say nothing about his continued care after our passing.

We urge you to fully support HCBS services through Medicaid. Our son's future support and happiness depends on you.

Regards,

Michael Avery

Ames, IA 50014

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my baby sister has needed help

Regards,

Mary Downing

715 Clinton Ave

Des Moines, IA 50313

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I believe in the Olmstead Act, the ADA, Section II and that people with disabilities, elderly, veterans, and children and families deserve the services and supports they deserve and need w/o denials.

Regards,

Garret Frey

3524 Midway Dr NW

Cedar Rapids, IA 52405

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

I have a spinal cord injury and am paralyzed from the chest down.

Community living matters to me because I am able to live independently. I live in an apartment by myself only because of home healthcare. I received services from my home health agency, and home health aides assist me With Using the restroom, Showering, getting dressed and getting in my wheelchair for the day. They also assist me in meal preparation and keeping my home tidy.

I am able to work because of community living and access my community to enjoy events and outings. Without community living services, I don't know what I would do.

Regards,

Evan Schultz

100 2nd Ave

Des Moines, IA 50309

KANSAS

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because no matter how far gone these people feel that they are when they come to these places when they come in these communities, they realize and see that they are cared for. They are loved in ways that they have never been before. They have connection that they have never known before. They connected to resources that help them throughout their lives. Sometimes these places are the difference between life and death.

Regards,

Jessica muckey

Wichita, KS 67210

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows my family to continue to care for our adult disabled son. HCBS dollars allow us to hire direct service workers and respite care workers.

If we did not have HCBS as he was growing, our family would not have made it through the stress of raising him. As it was I was diagnosed with PTSD from the stress response to raising him. While much better as an adult, he continues to need the supports that HCBS provides. In addition, I, too, benefit from those supports as I remain one of his primary caregivers.

HCBS has allowed us to access multiple life saving crisis and on-going mental health services. This includes regular therapy, occupational therapy, EMDR, psychiatric services, our local crisis center, law enforcement, and acute psychiatric hospitalization.

Please protect HCBS from cuts. Cutting this vital service would re-institutionalize the many people who have benefited from community living. Government continues to be the only organization that can operate “at scale” to protect the vulnerable. Cutting these services would be cruel, would demonstrate an unbelievable level of ignorance or even worse, indifference.

Please protect HCBS and Medicaid funding.

Regards,

Kris Ehling

236 S Dellrose St

Wichita, KS 67218

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I appreciate we experience the joy of living and working together for the benefit of everyone.

Regards,

Carolyn Hare

Leavenworth, KS 66048

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son is on disability. He barely makes it financially even tho he has his own home. if I didn't help him out now and then I don't know what he would do. He has constant pain plus other physical issues.

Regards,

Arlys Deckert

2902B Ivy Dr

North Newton, KS 67117

Submitted on Friday, December 5, 2025

Dear Members of the Special Committee on Aging,

12/5/2025

Lisa Barcus, Self-Advocate

Self Advocacy Coalition of Kansas (SACK)

2518 Ridge Court, Suite 238

Lawrence, Kansas 66047

Dear Congressional Committee,

Friends and family can’t live without paying bills. People with IDD (Intellectual and Developmental Disabilities) who receive HCBS (Home and Community Based Services) can’t live without paying bills, either. Kansas providers such Cottonwood, would not be able to pay people or provide services to people with IDD without HCBS services funding.

I live independently with the support of HCBS services every day. I work and get paid for two jobs. I have lived independently with support for 23 plus years. Without HCBS, I would be in pain and possibly not be able to live on my own.

I am asking you to not cut funding for HCBS services.

Respectfully,

Lisa Barcus, Self-Advocate

Kansas registered voter!

Regards,

Lisa Barcus

2501 Ridge Ct

Lawrence, KS 66046

KENTUCKY

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have 2 disabled kids who will become adults. And yes we work hard to make sure they get the skills and knowledge they will need. But for some kids and adults that will not be enough and they will need and do need the extra support. It means everything to the disabled people and their families that they have the resources to live as independently as possible with dignity and respect.

Regards,

Anetta Ali

Pleasure Rdge, KY 40258

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm an aging senior parent of a 40 year old daughter as a resident with the cedar lake foundation. The funds needed to support both adults and children and their families are vital.

Regards,

Julie Broyles

8016 Columbine Dr

Louisville, KY 40258

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows me to stay home to be a caretaker for my disabled mother and sister, rather than having to get a job and pay for a stranger to care for them or put my mom in a home.

Regards,

Nicolae Holley

2512 Waterford Dr

Bowling Green, KY 42101

LOUISIANA

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

July 16, 2025 - When dinner time turned serious at The Arc Caddo-Bossier's Hoyte Community Home, three dedicated Direct Support Professionals (DSPs) sprang into action to save a beloved resident's life. Their quick thinking and skilled response prevented what could have been a tragic outcome and exemplified the extraordinary care provided daily by staff of The Arc Caddo-Bossier's community homes, residential houses where groups of 6-8 men or women with developmental disabilities live and enjoy actives lives together.

A Routine Evening Becomes a Life-Saving Moment

At dinner time on Wednesday, July 9th, 55-year-old Trey B., a resident with disabilities, who has called The Arc Caddo-Bossier home for more than 32 years, began choking on his meal. What happened next showcased the professionalism, training, and dedication of

three remarkable DSPs who have devoted decades of their lives to caring for people with intellectual and developmental disabilities.

Georgia Carter, who has served The Arc Caddo-Bossier for nearly 25 years, recalls, "I turned around and looked towards Trey sitting at the table, and I noticed he was in distress". Without hesitation, she ran to Trey's side and began administering back blows.

Malcolm Cannon, an 18-year veteran DSP, immediately took over. "I attempted to help him, and he was starting to go down. His body weight was like dead weight, and we were attempting to keep him upright," Cannon explained. Working alongside Assistant House Manager Rasheeda Means, who has been with The Arc since 2000, the trio moved Trey to the adjacent living room to continue the Heimlich maneuver and the other life-saving efforts, following their training.

The three direct support professionals remained calm and focused and demonstrated the value of their extensive training in CPR, first aid, and emergency response. Carter called 911 while Cannon and Means continued working with Trey, adding the emergency operator's instructions to encourage coughing. With the support of 911 operator on the line and instinct and training at play, the team’s persistence paid off and the large piece of food that had been blocking Trey’s airway dislodged, offering immediate relief as color returned to his face and his breathing normalized.

"At The Arc Caddo Bossier, the safety and well-being of our residents is our top priority. We take great pride in our staff for their unwavering commitment, ongoing dedication to training, and their ability to respond effectively in emergency situations." says Deborah Hill, The Arc Caddo-Bossier's Director of Community Homes

For these three DSPs, saving Trey's life was more than professional duty - it was family caring for family. "I've been here 18 years, and the guys have become like family. It doesn't seem like a client-staff relationship. I've become close to all of them," Cannon shared.

Carter echoed this sentiment: "My kids are grown, so while these are not my kids, I can't go more than two days without seeing them."

"At The Arc Caddo Bossier, the safety and well-being of our residents is our top priority. We take great pride in our staff for their unwavering commitment, ongoing dedication to training, and their ability to respond effectively in emergency situations." says Deborah Hill, The Arc Caddo-Bossier's Director of Community Homes

Trey has been a cherished member of The Arc Caddo-Bossier family since March 26, 1993. Known for his love of sports, particularly volleyball and kickball, Trey has a special fondness for all holidays, with Halloween and his birthday being particular favorites. He

participates in the Conly Day Program and brings joy to those around him with his enthusiastic spirit.

"Trey is a very lovable person. He smiles a lot," Carter described.

The Arc Caddo-Bossier opened the first community home in Louisiana in October 1977. This innovative approach proved that there could be alternatives for people with intellectual and developmental disabilities that would allow those who lived there to thrive. Today, The Arc Caddo-Bossier currently owns and operates eight community homes throughout Northwest Louisiana, serving more than 50 people with around-the-clock care.

Kristen Powers, Executive Director of The Arc Caddo-Bossier, takes the responsibility of carrying the torch of this legacy very seriously and is proud of the continued work of the organization to serve people in this unique and innovative way. “Our Community Homes meet each individual's needs through person-centered plans customized to every person who lives in one of our homes,” says Powers. “This incident exemplifies how well-trained, dedicated staff make this personalized care possible. We are so grateful to have caring, talented, experienced professionals like Rasheeda, Malcolm and Georgia on our team!”

Regards,

Casey Jones

351 Jordan St

Shreveport, LA 71101

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

My brother, Troy Laurent, is 42 years old and has Down Syndrome. Troy has been living at a group home through Magnolia Community Services for the past ten years, since 2015. His move to Magnolia was a positive, life-changing experience. Up till that point, he had been living with our parents, who are now in their late 80s.

Our family first became acquainted with Magnolia when Troy became involved in their day-work program. For several years, he learned and developed gardening skills in their Garden Center, spending his days growing vegetables and going to places in the community such as Longview Gardens to help out in their gardens. Troy thrived in the day program- the structure and activities helped give more purpose and joy to his life, and provided him the opportunity to learn a new skills and socialize with peers. My parents were in their late 70s

at the time, and were becoming increasingly worried about what would happen to Troy when they became too old or sick to care for him. Already, they struggled to keep up with his long list of specialist doctor appointments related to his several medical conditions. In 2015, a space opened up allowing Troy to move into Magnolia's community-based residential program. He moved into a home with 7 other men with developmental disabilities, and there is a full-time staff person there at the house with them. Since moving in, Troy has learned to do so many things for himself, and so much more than we had thought he was capable of. He has gained in independence and maturity, and now lives a full life. Troy helps in doing his laundry, cleaning up his room, choosing his own clothes to wear, helps with cooking, and his social life is full. He goes to programs at Magnolia daily during the week. They had to discontinue parts of their day work program after hurricane Isaac unfortunately, but they are trying to build back many components that were there before the storm. He exercises at the nearby park with his roommates and people from the community, he attends dances and parties in the weekends that organized by Magnolia or other community groups, and there is always something fun going on at Magnolia each week that he gets to participate in. My parents and I get to see and visit with him regularly, but his daily care does not fall upon my parents ages 89 and 83, and they no longer worry about what will happen to him once they are gone. They know he is in a safe place, with staff who truly cares for him and supports him. This special program of community based services has been instrumental and vital in helping my brother Troy live his best life. He would not have the experiences, opportunities, level of care, and independence if he were still living at home or if he was in an institution. It is the perfect level of support for him. I urge you to continue to support these services. He deserves to live his best life. These community based services have given him the opportunity to live his fullest.

Regards,

Natasha Laurent

429 Florida Blvd

New Orleans, LA 70124

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me becausehelp

Regards,

Mary Horn

New Orleans, LA 70119

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps so many people

Regards,

Roland Thomas

2421 Paige Janette Dr

Harvey, LA 70058

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I love people

Regards,

David Bailey

9889 Hooper Rd

Baton Rouge, LA 70818

Submitted on Thursday, December 4, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it makes me feel included in my community. I actually feel as if someone cares about me.

Regards,

Bonnie LeBlanc

1200 Clay St

Kenner, LA 70062

Submitted on Thursday, December 4, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my 40 year old daughter has survived SAFE and SECURE at HOME with the help of 7 caregivers through her Medicaid Home Community Based Service waiver after a near fatal motorcycle accident 20 years ago! Read our story/ BLOG on VisitTheNothshore.com .

Christy&PJ Paulsell

Covington, LA

P.S. an “institution” will kill her PLUS none available for for diagnosis of Traumatic Brain Injury with Quadriparesis and PEG feed!

Regards,

Christy Paulsell

919 Woodsprings Ct

Covington, LA 70433

MAINE

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a special needs grand-daughter that has exceeded all expectations she'd acquire because of the services she received growing up. She was born with part of her brain missing, a hole in her heart and missing valves, and only one kidney. She will never be able to live alone but she is a wonder to us all. Thank God for all the services she received. Every disabled child deserves this.

Regards,

Lynne Spencer

22 Iron Mine Hill MHP

Gardiner, ME 04345

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because everyone needs a place to live without fear

Regards,

Don LaRouche

19 St Mark St

Skowhegan, ME 04976

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because wiithout I'd be homeless.

Regards,

Cathy Smith

62 Pine Grove Terrace Rd

Oakfield, ME 04763

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me

Regards,

roger lambert

3 Post Office Square

Kennebunk, ME 04043

MARYLAND

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I do not want to loose my services

Regards,

melissa sachs

15250 Siesta Key Way Apt 273

Rockville, MD 20850

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because people like living near their friends and family. They want to keep their same doctors.

Regards,

Arlene Paterrov

Clarksburg, MD 20871

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a School Sister of Notre Dame. We sisters worked for years teaching and ministering among the people of our nation. Now as we age, if we do not have the benefit of Medicaid HCBS we will be on the street. These are trying economic times. Without Medicaid HCBS we will have neither health care nor a place to live.

Regards,

Rita Bueche

8404 Charles Valley Ct Apt C

Towson, MD 21204

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because for a long time I wasn't part of a community but a burden to it. I was addicted and homeless and lost. I have since with the help of Medicaid gotten clean and have gotten my outs dated pacemaker with leads that moved and endangered my life without medical I could not have gotten that life saving surgery. Without good program snap I wouldn't be able to nourish my body to heal and have resources to get what I need to be healthy safe and alive to grt my life back. That is what the public assistance has done for me. Without them id die definitley. My life is worth so much and so am I. Thank you for your time and consideration during these terribly trying sad times.

Regards,

Sharon Brecker

Baltimore, MD 21222

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm able to make my own best decisions and follow my specific daily routine, surrounded by my family and friends and neighbors who know me. An an older mom with a physical disability, parenting can be especially strenuous. My teenage son receives autism waiver HCBS services that keeps our family together, functioning as one progressive unit towards our goals. His caregivers have become part of our family and help to keep us moving forward. If our son's HCBS services goes away, our functioning family might be stalled and split into pieces.

Regards,

Tonya Gilchrist

12528 Palermo Dr

Silver Spring, MD 20904

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because My Son Autistic with Other Diagnoses & Needs help With Everything

Regards,

Lorretta Sisco

6179 Dorlon Dr

Rock Hall, MD 21661

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because the quality of life for my adult disabled child allows him to not only be a blessing to his family, friends, and larger community, but his needs are managed so efficiently (by family who knows them intimately) that the impact cost of caring for his needs are lessened on a small rural community's already limited social service infrastructure

Regards,

Gayland Carlisle

13361 Frg Br Dr

Greensboro, MD 21639

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because The Reason community living matters to me is that I have friends they are like.

Regards,

Tiffany Griar

50 Monroe Pl Apt 706

Rockville, MD 20850

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it gives society what it supposed to give it: LIFE

Regards,

A.J Brown

4102 Queensbury Rd

Hyattsville, MD 20781

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter Jackie is 24 years old and has Down Syndrome. She has participated in community based support program through the DDA waiver process in Maryland. She has 1 to 1 support person that takes her to all of her community based activities including work at the YMCA; horseback riding; bowling; movies and social events.

The largest drawback with the current system is the lack of portability if we were to move to a different state her services do not follow her. This needs to be fixed. Jackie benefits from these services and would have no independence if these. Support service went away.

Regards,

Robert Taishoff

228 Mountain Laurel Ln

Annapolis, MD 21409

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because our adult son is autistic and needs these services. He has benefited so much from the educational support, community support, and work support from The ARC of Howard County. He needs to be able to live with independence, dignity, and a deep connection to his community.

Regards,

Judith Furie

8248 Glen Ct

Jessup, MD 20794

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son with Down Syndrome has friendships out side of the home and will be cared for when I(his mother) is gone.

Thank you

Regards,

Marcia Canfield

3455 Mar Lu Ridge Rd

Jefferson, MD 21755

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it is very import jet for people with disabilities have freedom and feel like a regular person and feels so special to them for their future

Regards,

Amity McGinnis

9315 Ridings Way

Laurel, MD 20723

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

The services that my 28-year-old daughter with Down Syndrome has received have changed her life significantly. These services give her a sense of independence that all citizens should experience.

Regards,

Kevin Carbaugh

13669 Samhill Ln

Mt Airy, MD 21771

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son has severe autism. I believe we need a place that is a cross between assisted living and institution living in addition to group homes for those that are not as severe. A place with some professional on staff. A place with some cameras to make sure there is no abuse. Non verbal with intelligence disorder is harder to deal with. There needs to be a fence around it to keep them safe. A movie-rec room so they can socialize together. This model will allow the staff to help each other when one of the clients is in crisis. i am also for the group homes for those that can live in them that can't live alone. I am also for supported staff coming to the client home to help keep them in the family home and their home if it is left for their use. Medicaid is how these people are taken care of. My son will always need a person with him due to his intelligence disorder and severe autism. We should take care of the ones that cant work.

Regards,

Veronica Hippensteel

109 Earliana Ct

Pasadena, MD 21122

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it cared for my son Stephen. He could not walk, could not talk, had to be diapered, had to be fed, could not see or hear. Thankfully, he died two years ago at the age of 54.

Regards,

Patricia Holllinger

1000 Weller Cir Apt 228

Westminster, MD 21158

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps give individuals independence, build skills in the real world, while in real time. They have better access to care, nutrition, and individual support vs. institutional services, which btw are under staffed, and filled untrained staff. They are infamous with abuse, neglect, and financial theft. Please don't take funding from community based programs.

Regards,

Jennifer Dapkins

3211 St Augustine Ct

Olney, MD 20832

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have worked with people for 30 years that have been disabled and I myself have been disabled the last seven years. I've seen people who have no family and are dependent on programs like medicaid, social security.....

Please realize that this is survival for many who are challenged by life circumstances.

Regards,

Sue Italiano

Parkville, MD 21234

Submitted on Wednesday, December 3, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am approaching 86 years old. I cannot keep up with the dr. appointments my daughter needs. Her home and supports brings some independence to her as well as some social life. This is crucial to her well-being both mentally and emotionally. She is not able to read, write, cook, drive, shop, or understand dr. directions for her meds. This gives me peace-of-mind that she will be cared for as she ages. This is crucial for both of us.

Regards,

Judith Weightman

3280 Centennial Way

Frederick, MD 21704

Submitted on Monday, December 8, 2025

Dear Members of the Special Committee on Aging,

Two of my five adopted child are or will be benefiting from Committee Living supports in their adulthood.

My daughter (21) is already a part of Maryland's Transitioning Youth program under DDA, living in a shared supported living apartment with rotating caregivers; and her brother (20) is slated to access his services next year.

Both have lifelong developmental disabilities. Things like managing time, handling money, scheduling appointments, making healthy eating, hygiene and sleep decisions all require external help. My husband and I could in no way provide 24-hour supports for both of them, in addition to all our other responsibilities. However, WITH the appropriate supports and accommodations, both of them have jobs, attend a social group for adults just like them, can cook basic meals, volunteer to help others, and our daughter can even drive in a

limited, well-practiced area, like to work and church. Take the supports away, and they'd both be on screens, unbathed, missing their medication, and eating junk food; but WITH supports, they can live and work and commune with everyone in the community, give back, pay taxes, and have meaningful, productive lives.

We are VERY grateful for their supports and to know they will be cared for after we are gone.

Thanks for taking the time to read our story.

Regards,

Kim Fauth

16 Country Mill Ct

Catonsville, MD 21228

MASSACHUSETTS

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have 2 disabled teenagers level 3 autism? epilpsey, pica.They need the state to stand up for them and stop cutting thier funding..Vets and special needs people need more

Regards,

Jessica Roy

16 Glenda Ave

Wareham, MA 02571

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am on disability. Harbor one Bank told me I have to remove $50,000. Because on disability I can only have $2000. In the bank. Is this true ?

Regards,

Muriel Slack

Bedford St

Abington, MA 02351

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

I have Medicare primary and MassHealth (MA version of Medicaid) secondary for insurance coverage. They pay for vital personal care attendant (PCA) services and durable medical equipment (DME) like customized manual wheelchair I received after 6 level completion process and nearly 4 months. I also use a non-invasive vent to assist breathing when sleeping/laying down due to compromised respiratory muscles from a congenital form of muscular dystrophy. The vent runs about $3500 per month and without insurance coverage would not be affordable and I'd risk respiratory failure without it's use. This loss of DME coverage and PCA services would not only impact me but also my family and my advocacy work. The impact would not be static but spiral out and have broader implications to community overall beyond myself and many disabled persons (apparent, non-apparent, chronic illness) I know live in similar continuum.

My mother is 74 and has same coverage, uses PCA services that help with meal prep, hygiene, light housekeeping, shopping, clinic escort, home management. She also has visiting nurses who help with psychiatric and diabetic care and continuity of med intake. These in-home services allow her to remain community-based and independent. She is able to age with grace, dignity, and autonomy and participate in community as much as she is able to do so.

Having beneficial policies with budget allocations aid individuals, families, and whole communities to thrive.

Regards,

Heather Watkins

56 Seymour St

Roslindale, MA 02131

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows the disabled to support one another and have active lives.

Regards,

Michael Driscoll

225 Lincoln St Apt D1

Duxbury, MA 02332

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because without it, my autistic son would not have the supports he needs. He is in a 24/7/365 behavioral group home, for which he waited 7 years. I had to get old and sick in order for him to move up the priority ladder and move out of my home. He outweighs me by 100 pounds and is 8 inches taller. Adults with severe autism/ID/DD are not going away and need a variety of housing models. He is in a 5-person group home because that is the only current model available to support him. "Shared living" would mean the provider can evict him when his care is "too much to handle." Believe me, that would not work for him.

We signed the Medicaid/HCBS waiver because at least that way, our state can get some federal funds, financial help, for providing housing and supports for people with disabilities. Social Security alone would not be enough to pay for rent and supervision for him.

We need other options for severe autism such as farmsteads, intentional communities, and intermediate care facilities. Community can be defined different ways and safety should be a priority.

Regards,

Alice Taylor

81 Ellison Park

Waltham, MA 02452

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I care about the elderly.

Regards,

Sofia Montemayor-Thomas

21 Seneca Rd

Acton, MA 01720

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

I've had the extreme privilege to work with and for the men and women of New England Village inc for 35 years

I've seen the the potential and opportunities to learn, grow and get competitive employment because of the services they received and the direct care support they received in their community setting

They live longer happier lives in community base settings

I have celebrated 70, 80 and even 92 year-old birthdays with my residents

Because of the care they've received

Regards,

James Scott

25 Tobin Terrace

Whitman, MA 02382

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because of the people that I serve as an employee at Berkshire County Arc. Without the services that we provide, over 800 people would not have the opportunity to pursue their dreams of living an independent life and being a part of the community.

Regards,

James Ivy

190 Pittsfield Rd

Hinsdale, MA 01235

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

As a 24 year old woman who hears using cochlear implants and has intellectual challenges, my daughter Hannah would have a very limited ability to actively engage in her community and have meaningful, enriching experiences with social peers without access to Medicaid funded home and community based services.

Hannah is wonderfully outgoing and is up for any and all experiences. Today Hannah was able to participate in her day program where she came together with several friends to volunteer for Meals on Wheels to deliver lunches for seniors in Plymouth, MA. Her senior friends look forward to her visits as much as she eagerly anticipates seeing them and their pets. She knows every senior by name and remembers their birthdays flawlessly. Later, she went to a local horse rescue and assisted in caring for her favorite injured or elderly equines. Following that, she returned home to her 2 room mates and a personal care assistant who helped the girls make dinner, take showers and relax with holiday craft projects. Each night she calls and gives me an update on how her day went. She is always happy to share her activities and plans and to report on new horses at the barn or a mother cat who just delivered kittens at the animal shelter where she also volunteers. It's with great pride that she notes she lives "in an apartment like my big brother" and has an independent, though highly supported life. She sees meaning and value for the volunteer work she engages in and gets excited to plan her schedule each week.

If these residential and community services were taken from Hannah, she would need to return to living with me. This would drastically limit her social options and daily activities. She would be heartbroken without her varied and active program. It would also require that I no longer work as a geriatric speech pathologist providing hands on care for stroke,

accident, cancer and rehabilitation patients. My job cannot be performed remotely and the financial loss would be devastating to us. Without community and home based services I would have to replace my roles as a her mother, friend, shopping buddy, gardening pal or coffee date and become her full time caregiver instead. Whereas I know I can provide for her physical care, I could never give her the enrichment that her Medicaid home and community based services allow. Loss of services would be heartbreaking to us, as well as Hannah's senior friends, her animal friends and her large social peer group. It would also remove much needed speech therapy services from our local nursing home. Removing Medicaid HBCS would remove so much of value from more than just the direct recipients, it would diminish our whole community. Please continue to support the programs that bring health, happiness and community engagement for adults with disabilities.

Heidi Harrington Roberts

Regards,

Heidi Roberts

14 Cooke Rd

Plymouth, MA 02360

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a relative who has achieved so much in that setting.

Regards,

Sally ruscito

32 Harris St

Dedham, MA 02026

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son is about to graduate high school. He has autism and epilepsy. Without support he would have to live at home and this would be very

detrimental to his mental health and his self efficacy. I work with older adults in my professional life as a Physical Therapist. They want to be in their own home most of all. Without support they would need to be institutionalized sooner at a greater expense to them or to the taxpayer. Please help my son and my patients live independently with support in their homes as they need. It means the world to us!

Regards,

ALEKSANDRA GOLBERG

6 Bourne Rd

Foxborough, MA 02035

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because people should feel included in society just like anyone else.

Regards,

Nick Figuerado

41 Sunnybrook Rd

Springfield, MA 01119

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son who is autistic and non verbal benefits across multiple communities. He needs this in order to live a life of fulfillment within his communities. He currently lives with us his immediate family and he attends a day program as well where he does community service as well as participate in many community programs for elderly and/or disabled individuals both adults and children. He has been so happy at participating and enjoying spending time with his peers and staff as well as therapists and providers. Please help us maintain these benefits so our children can continue their path to independence and a live filled of fulfillment and happiness. Thank you!

Regards,

Luxanyaris Zayas

496 Main St

Hudson, MA 01749

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my husband and I have two additional needs children. We are in constant fear for the future. We both try to keep ourselves as mentally and physically health as possible so we can live as long as possible to protect and care for our children. Sleepless nights worried about what will happen to them when we die.

Regards,

Jennifer Mock

5 Matthew Cir

Oxford, MA 01540

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I began my career working in an institution which housed people with ID/DD. Housed is a term I use loosely. Warehoused better represents the experience of the people kept there. I transitioned into the community with individuals who had no basic home living experience. No refrigerator, no separate rooms to sleep and live in. It was a shock for many folks who spent their lives living and sleeping in a room with 15 or more other people to have a room to themselves. It took a bit of getting used to. Once people realized that they had their OWN personal space, the reaction was beautiful. Imagine never being able to call something your own…and then you can.

The community also offers the opportunity to get to know people and make friends. Friends are people who care about you and are concerned for your wellbeing. Sadly, I have experience too many funerals where of the 10 people in attendance only 1 or 2 were not paid to be there. Living in the community and joining groups, attending church, being seen

around town has led to relationships which ease the loneliness felt by many marginalized members of the ID/DD population. I cannot imagine going back.

Please support opportunities and funding to keep the progress going in a forward direction. None of the people I know want to go back to the warehouse that is an institution.

I have been supporting people for 45 years. There is still more work to do.

Regards,

Robin Marques

61 Rhode Island Rd

Lakeville, MA 02347

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my brother, who has developmental disabilities as well as physical health issues, lives in a group home along with 3 roommates who also are disabled. The staff works hard to make a nice, pleasant and safe home for these individuals. They attend to the many needs of the residents to keep them comfortable and happy. My brother is doing well under their care and is living a happy life. He loves his roommates and his home. He is unable to care for himself and he needs the care and support of the staff at the home to keep him healthy.

Regards,

Mary Richinick

12 Wintturi Rd

Westminster, MA 01473

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a child with disabilities and I care about families with all types of disabilities. We should be adding to the programs, not decreasing the programs.

Regards,

Maureen Cumming

5 Mirabeau Ln

Lynnfield, MA 01940

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it is so much healthier and rewarding then being in a group home.

Regards,

Eileen Velez

1153 Hyde Park Ave

Boston, MA 02136

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because. I want keep being independent and ect.

Regards,

Joe Parzych

14 Elm Terrace

Greenfield, MA 01301

Submitted on Tuesday, November 25, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because both my stepson and stepdaughter live in residential housing. My stepdaughter, who is higher functioning than her brother, is able to work at McDonald's and study for her GED. Also, her house manager has taken her under

her wing. They've traveled to Salem, MA, and New York, where they did many fun activities together. If it weren't for her program, she wouldn't have this enrichment in her life.

My stepson, who needs more help, attends a school for adults with special needs. He gets wonderful individualized care. He is well liked there. At his residence, staff faithfully bring him the 30 miles every Saturday, there and back, to visit his Dad and me.

My stepson is 37. My stepdaughter is 32. They both have an excellent quality of life at their HCBS, and I don't know what they'd do without them.

Regards,

Nancy Garrett

170 Shays St

Amherst, MA 01002

MICHIGAN

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I live alone and my children are not close to me! I am 71 with Lupus, Fibromyalgia and COPS! I drive when I can, but since I have a tendency to pass out I stay home. If there were no organizations to help we seniors would be in trouble!

Regards,

Terri Teamer

22400 15 Mile Rd

Clinton Township, MI 48035

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because For me, community is more than just a collection of people living or working near each other—it is the heartbeat that makes life meaningful, especially for someone like me who navigates the world with a disability. Being a disabled American often means facing barriers that others may not see: inaccessible spaces, assumptions about what I can or cannot do, and the constant need to prove that I am capable and deserving of the same opportunities as anyone else. In these moments, community becomes not just a comfort but a necessity.

Community is the people who notice when I need support without me having to ask, who celebrate my accomplishments at work, and who offer patience and understanding when challenges arise. It's the coworkers who respect my abilities and provide a space where I can thrive, the neighbors who lend a helping hand without hesitation, and the friends who check in simply because they care. These connections, no matter how small they may seem to others, are profoundly sustaining.

But community is also more than support—it's encouragement, reassurance, and a shared sense of purpose. It reminds me that my daily efforts, the work I put in, and the contributions I make are seen and valued. Even on days when I feel exhausted, overwhelmed, or frustrated by accessibility hurdles, community whispers to me: "You belong here. Your presence matters. Keep going." There is a gentle strength in that knowledge, a warmth that makes life feel a little lighter.

For someone like me, who goes to work every day, community is both practical and deeply personal. It's the systems that allow me to do my job effectively, the colleagues who treat me as an equal, and the small acts of inclusion that affirm my dignity. But it's also the unspoken understanding, the smiles, the check-ins, and the moments when someone simply says, "We've got you." That is the kind of community that sustains me—not just physically, but emotionally, mentally, and spiritually.

In short, community is about connection, reciprocity, and belonging. It's about giving support and receiving it, advocating for accessibility, and creating spaces where everyone—regardless of ability—can participate fully. It's a lifeline, a reminder, and a source of strength. And if you take a moment to look closely, you might see that building this kind of community doesn't just help people like me—it enriches everyone, because a truly inclusive community is stronger, kinder, and more resilient.

Regards,

Roger Roper

1184 Lexington Pkwy

Ypsilanti, MI 48198

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am 67 years old and I use a cane or a walker. Having more accessible housing for low income Seniors and Disabled people living on Social Security is crucial.

Regards,

Marianne Paskiewicz

1754 Willis Ave NW

Grand Rapids, MI 49504

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

It's awful what's happening groceries are higher My rent went way up and clothes are expensive even dog food. This is freaking ridiculous Tell Trump to leave office. I mean I know that's no possibility but something has to be done to get this idiot out of office. He's hurting the US citizens

Regards,

Linda Greenhill

2645 Riverside Dr Apt 205

Trenton, MI 48183

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, I am on a fixed income. I'm 61, became disabled in 2012, Medicaid was great when I became disabled because it covered my 20% that Medicare would not cover. This year 2025 I was told that I will no longer receive the full

coverage but just to cover medicine. I have labs, test and I found out I have a blockage and have to take more test at a hour away hospital. It will not be covered, I have to pay $4000. I thought Medicare would pay at least 80%, but it was totally denied. Where I live (in Flint) the equipment isn't reliable, therefore my heart doctor sent me to a bigger hospital to take test. I am going to a different insurance that will accept me being able to take test for treating my heart. I know I would need a stint but how can I get one of both Medicare and Medicaid will not pay.

Regards,

Genava Teverbaugh

Flint, MI 48505

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my stepson, Benjamin Hirsch, has thrived since moving into a "pod," affiliated with JARC in Michigan. He is 29, cognitively impaired, and illiterate. He has both intellectual and neurological deficits that make it impossible for him to enjoy complete independence. But because of these benefits and services (hours for caregiving, social activities, and Medicaid), Ben and his roommate (who is autistic) qualify for 24-support services that afford them the independence they need to feel valued in the community where they both live.

Ben also has a job. He was trained by Project Search, which help young persons with intellectual and developmental disabilities secure competitive employment. He works 20 hours a week delivering and sorting linens at Henry Ford Health Systems in West Bloomfield, MI.

I must say, Ben is one of the happiest humans I have ever known -- much of this is due to the independence he feels by living in his own apartment and going to work five days a week.

Programs like Medicaid HCBS are essential and make a difference in Ben's life and so many others' lives. If he did not have these programs, he would not have trained caregivers supporting him, teaching him life skills, because it would be prohibitive without assistance from these programs. He would lose the feeling of independence as well because we would not be able to afford to support him in an apartment and also pay for 24-hour care. Most people would not. His care, even with community-based services, costs our family

nearly $3000 per month. I don't want to even think about what might happen without Medicaid HCBS.

Ben works so hard. He is a productive member of society. He is thriving on his own. He and every human with any disability deserves support from this great country.

Regards,

Kimberly Lifton

7139 Suncrest Rd

MI 48322

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it had made taking care of my adult daughter a little less stressful and less financially stressful. Granted the special needs community does benefit from the programs, it doesn't even begin to cover everything that they may need. I honestly do not k ow how I would have been able to stay in my home with her if I didn't have the opportunity to become her home help provider and be paid. However, i don't think there is enough programs for the familied that choose to have their loved ones live with them. Not enough programs or funding for these programs for individuals past the age of 18yrs old. A lot of times special nerds do not change once someone turns 18yrs old. In my experience it felt like there is all this help for your special need loved one only if they are under a certain age. After they age out of the school system at 26yrs, its like the special needs community is pushed to the back, forgotten about. As if they were saying that you don't have much else to contribute to society after you age out of the school system. So the programs that are available have made my daughters life ok after aging out of the school system but more needs to be done to ensure these individuals are valued at ANY age. After my daughter turned 26yrs old, a lot of her services went away because she wasn't in school or she was too old for programs. For instance, i had no clue that she could have had Childrens Special Health Care Services for a few more years. By the time i found this out, she was a few months from the programs cut off age. These programs for what they do help with, allows my daughter to live with dignity and feel safe at home with her family.

If we didn’t have these programs It would make it extremely hard to properly care for my daughter. A lot of the financial responsibility would fall on the family. What medicaid covers for her doesn't even begin to touch on what she truely needs. Like whomever is making

these decisions on what to cover and not to cover, does so by drawing a decision out of a hat. Not based on actual need, making us fight for months sometimes years to get something covered only to be told you need a new script for whatever you were trying to get covered. It needs to be made easier to get items covered. Especially the way they decide whaich meds to cover and not cover. Some individuals cannot afford their life saving medicines or they can only take certains kinds. If these programs were to completely go away, there would be so much more poverty and neglect (by no ones fault of their family) because we couldn't get the proper services to take care of our loved ones. The special needs(a blanket term to encompass all types of disabilities) community is A LOT bigger than you even can begin to realize. Not having these programs i feel eould increase mental health issues in caregivers because of the added financial stressors and becausr of the feeling of being ignored and bring made to feel even less important than now. Honestly it feels at times i get told well tough cookies (but in a much less nicer words) you're on your own, we don't care if your loved one is an adult. When programs go away like this, it gived a feeling likr they dion expect the special needs co.minity to live past adulthood. My local county has done away with the only program that would have helped my daughter transistion from going to school everyday to not being able to do much of anything because of no services. It was the day program for the special needs community that allowed them to be more integrated within the community they live in. I use to see special needs community all the time. Now im lucky if i even see them anymore unless their families take them out. This program i feel helped the not special needs how to act, to accept and not be afraid of the SN community and to show them that just because they're SN, doesn't mean they don't have anything left to contribute. Also it needd to be more inclusive interms of the programs that is out there. EVERY SINGLE PROGRAM i have tried to get my daughter into had turned me away brcause they do not have the staff to care for my daughter. They rather can take care of more able bodied special needs individuals. So what is the purpose of these programs if they cannot serve the whole special needs community?

Regards,

Diana Bush

1190 Jackson St

Dansville, MI 48819

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have seen the direct impact that it has on people with disabilities and older adults. As someone who has worked at a local Community Mental Health agency as a developmental disability case manager and at an Area Agency on Aging, I can attest that the individuals who had the opportunity to live in the community had much better outcomes than those who were forced into a nursing home because of their financial situation. It is hard to explain the heartbreak that I saw when I had to tell people that their only option to receive the care they need was to remove them from their community living arrangement and place them into a long term care facility. The clients I worked with had friends and support in the community, they were able to participate in activities they care about and be a part of something. When that was taken away from them they felt they had nothing left; no reason to continue living. Choice is what matters most in ensuring people can live a meaningful life and I believe that HCBS is vital in ensuring that choice.

Regards,

Kaitlin Grant

212 Leslie St

Lansing, MI 48912

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because.

Regards,

Ivy Bivins

16606 Archdale St

Detroit, MI 48235

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it has without exaggeration, saved my family's lives. My brother has autism and is on the severe side of the spectrum. He has just spent

his first year in a Medicaid HCBS group home and he is positively thriving. My parents took care of him for thirty years prior on their own and despite their best efforts, it was killing them taking care of my brother. Instead of spending their retirement years living well earned rest, they were still taking care of a strong, high needs adult. As they have aged they were not able to keep up with his needs alone. My brother could not go outside the house ever because my parents could not control him. As a result, they were all prisoners in their home. My brother exhibited violent behaviors due to his imprisonment and would lash out at my elderly parents. I spent many nights living in fear that I would get a phone call that my brother murdered one or both of my parents. But then my parents finally asked for help by the state. My brother initially spent some time at the Caro State Hospital where he learned management skills for his behaviors and his medication was adjusted to a proper dose. When he was stabilized, he then joined a HCBS group home and not only has his life improved but so too did my parents'. My brother is smiling, looking healthier, and doing things in the community for the first time in decades. My parents are also improving. They are less sullen and haggard in their expression, they are able to spend quality time with other family members, and can go out to a restaurant together for the first time in twenty years. It is no coincidence that their increased happiness and health started when my brother moved to a group home. Medicaid HCBS programs save lives. Without them my parents would undoubtedly live shorter lives, my brother would be still the angry, restless person he once was, and I would still be living in fear of what happens to my family when a crisis inevitably occurs. Medicaid has been attacked quite a bit in the last few years. I believe the people responsible for these reductions want to reduce costs but at the end of the day, these reductions just cost Americans more in so many ways beyond just money. Do not reduce Medicaid HCBS programs, people's lives depend on it.

Regards,

Jonathan Howlett

24706 Schroeder Ave

Eastpointe, MI 48021

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

I am writing on behalf of my 37 year old nonverbal, severely cognitively impaired and autistic brother. After the unexpected death of his mother and sole caretaker 6 years ago, he was left with no where to go and began residing in a community supported group home.

We were so grateful to find a great place for him and he has since thrived. If not for his services, he would not be able to survive. He requires 24/7 care and supervision. He needs help with all personal care needs, safety, and health issues. Because of his supports, he is able to live in the community, attend skill building, and lead a decent life. Without these services he would have no where to live and wouldn't be able to have his basic human needs met. His needs are too great and the loss of these services could cause him serious harm. These services are vital for the survival of this community. They deserve care and dignity and cannot help themselves. There are no other options for these people and their dependence on these services must be recognized and valued. These services are life changing for all involved and must be protected at all costs.

Regards,

Christina skeltis

22045 Rio Grande Dr

Macomb, MI 48044

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my very disabled son has lived in an apartment for 20 years with parent help. Who will do the paperwork when we are gone? Who will hire needed support services like cleaning (which he can pay for) after we are gone? I'm a boomer. Our adult disabled childfdn will be a big issues after we start to die.

Regards,

John Gedda

455 W Maryknoll Rd

Rochester Hills, MI 48309

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because if I did not have this access I would be unable to live independently

Regards,

Lisa Chadwick

18234 Lenore Ave

Detroit, MI 48219

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have worked in institutions, and raised my son with severe impairments at home. The difference in quality of life between these settings is staggering. If one has ever been admitted to a hospital for a week or more, one can imagine what their life would be like if that was where they were permanently "placed." Institutional settings are not healthy for anyone. Close proximity creates rises in communicable disease, and increased hospital admissions as a result. The individual is more often than not enslaved to institutional routines- like staff mopping floors in the middle of the night, or being taken out of bed at 3am to be showered because that's what's convenient for staff. Meals are often cheap and lacking nutrition. Houses, like group homes, are often lacking cleanliness. Build up of dust and other allergens goes ignored. A look in the cupboards at dishes people are fed from will reveal, too often, food that has been baked on by a dishwashing machine. Staff are too frequently underpaid, overworked, and mistreated/abused if they develop any sort of connection with residents, and try to advocate. This translates to the quality of care they give the human beings they were hired to care for. Guardians and family members are retaliated against if they try to advocate. Executives earn lucrative salaries while rarely visiting the instituions they oversee. Families like mine, a single mother and a disabled adult child, are forced to give their child up to a system that uses that person as a funding magnet, receiving funds that are mismanaged to the detriment of that individual. I became disabled myself trying to care for my son at home. I was then told there were no more funds available to keep my child home, safe, and thriving. When the system took him, it was paid 5x the amount it paid my son and I put together through SSDI and Adult Home Help. I watched his quality of life deteriorate, watched him fail to thrive, after 2 decades of fighting for him, fighting for his life to be one in which he could smile, and laugh. I watched the light go out of his eyes, then I watched him die of asperate pneumonia, after years of advocating for better staff training- as in not feeding him too fast for him to swallow, and making him literally inhale his food. By the time they realized something was wrong, the hospitalists said it was too late. If my son and I had been granted half of the funds it took to take him away from me and put him in a place

that would eventually kill him, I could have kept him at home until his natural end. I could have hired help so I did not work myself into exhaustion leading to neurological disability. I could have continued educating people about people like my son, and what they give to the world by their existence alone- joy, knowledge of the spiritual and divine, how to be good humans. But that was all taken when he was. When the system decided to spend 5x the money to put him in an institution, and the subsequent hospital admissions that cost even more, and cost him his life. I still dream of what life could have been like if "The Village" actually existed, and it had helped me keep him home and safe and happy. This is what Medicaid, when spent appropriately, can help people do-stay in their community, with their families, and friends, contributing their particular gifts and teaching what we can not otherwise learn. Please be The Village. Be one of the reasons people like my boy get to stay where they are loved, and safe.

Regards,

Bethann Robins

312 Pratt Rd

Kalamazoo, MI 49001

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

People with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. HCBS help make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.

Regards,

Skip Bleecker

8310 E Remus Rd

Mount Pleasant, MI 48858

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. HCBS help make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.

Regards,

Stephanie Meacham

740 Koula Rd

Marysville, MI 48040

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

He was just a baby, born with Williams Syndrome, when I realized how hard he would have to fight for the life we had dreamed for him when I was pregnant.

As an adult, he wanted to work. He wanted his own money and the pride that comes with earning it. He needed more than the 90 days that rehabilitative services allow for job coaching. Because of HCBS, he was able to hire a job coach to work with him until the employer said "we've got this." Now 27 years old, has held a job for over four years with natural supports.

As he has watched his high school classmates go to college, get jobs, have their own homes, get married, he has wanted that too. Nobody wants to live with their parents forever. Because of HCBS, he now lives in his own home, with a roommate, and the 24 hour staff required to support them safely in that home. The staff, who also needed jobs, are now working in a meaningful field and contributing to the economy and supporting their families. One who actually wants to go back to school to become a social worker so she can help more people like my son live their lives to the fullest.

This is all thanks to HCBS.

Regards,

Beth Kohler

15206 Woodpine Dr

Monroe, MI 48161

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I believe they should be safe, fun and free for people of all diversity to thrive in

Regards,

Maxxcell Higdon

2634 Wildwood Ct

Lake Orion, MI 48360

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

TRUMP HAS TO BE STOPPED, HE OBVIOUSLY HATE THE DISABLED, WOMEN, CHILDREN AND VETERANS AND THE AGED.

Regards,

Richard Smith

17393 Harman St

Melvindale, MI 48122

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

My daughter just entered her forever home last May. We thought she was a bit young at 26 but a spot open in her perfect location and we took it.

Many months later I asked another parents how his daughter was doing g and he used a word that never came to mind. He said she is becoming very “independent” this is a world in my wildest dreams I could never imagined describing my own daughter yet he said it all. My daughter, leaving our home and my micro managing, with the excellent direct care workers had become independent!! It is something I never imagined as an option and

because of these homes she achieved greater then ever thought, while surrounded by a family of ladies, a caring staff and a company, Jarc, that puts there residents first!!

Milaine

Regards,

Milaine Grossbard

25428 Woodvilla Pl

Southfield, MI 48075

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

See deafmed, my name, not my disability or what I did for a job. I'm listed on deafmed, find me and see many others too like me. Vocational training and rehabilitation helped immensely, thank you. Now, I'm navigating being old. I don't get paid weekly as a traveler anymore, not even biweekly anymore, it's monthly. I'd appreciate resources.

Regards,

Michael Larsen

3412 Loretta Ave # A

Jackson, MI 49201

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm a 61 year old mother and grandmother my parents are both deceased my mother passed away in 1987 of brain cancer I was only 23 I my father was a Korean war veteran he died in 2019 of a stroke I receive food stamps and insurance through the state of Michigan I have not been able to find a job since 2006 I have health issues and I make it known on my applications because I do not lie I have an avm on the front left side of my brain, fibromyalgia, arthritis and frequent headaches but I do not qualify for disability I only receive $298 a month in food stamps and my health insurance and if I lose that I will not be able to eat or take care of my health needs it's not that I don't want to work it's because no one is hiring people like myself

Regards,

donna carr

7299 Wood

Center Line, MI 48015

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because living authentically besides being hooked up to a tv or Nintendo switch 2. Going to pride events and book clubs.

Regards,

Frank Vaca

516 Laurens Way

Potterville, MI 48876

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it takes a village not only to raise a child but to raise up one another. Being born different shouldn't mean having less value or experiencing less in life, community living allows us all to live life to one's full potential. Why would anyone want to take that away from another person?

Regards,

Pauline Bynum

28778 Coleman Dr

MI 48138

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have personal experience volunteering for individuals who have disabilities; I also worked with these individuals during my internship training for my Music Therapy major, and I myself am diagnosed with Autism Spectrum Disorder. Therefore, it would mean a lot to me if you kept the Medicaid HCBS and continue making it more accessible and known to individuals who are not familiar with it.

Regards,

Ashley Hafeli

3374 Regency Dr

Lake Orion, MI 48359

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am 66 yrs old. I have went through the worst 2 years of my life starting in 2023. I had catoract surgery in August and September 2023 that left me more blind then before the surgery.

March of 2024 I had a house fire. Was able to stay in my home with the support of a generator, but fuel for 32 days was $800 to run the generator. That left my savings at $0.

My truck was vandalized and repairs have cost me over $1,200. Still paying this off. Then I was forclosed on my home of 30yrs for back taxes totaling $3,000. The treasures department would not work with me. I had $1,500 in my savings to give to them and the remainder to be paid the next month. Instead of excepting payments the sold my house to a housing development located in Texas. I am being evected as of Friday the 21st of November. I was scheduled for court on that day, but was unable to attend. I live 25 miles away for town and do not drive. I as have recently been diagnosed with aggressive breast cancer. I am experiencing bad health at the moment. So I was unable to attend

The eviction process in court. My main concern is there are insufficient amount of housing in this area. Actually there is none at the moment. Most have waiting lists of over six months.I do not know what to do.I do not know where to go.I do not have anybody to help me.I have no family or friends. I have tried every organization that has been suggested for me with no luck. If there's anything that this area needs, it's senior housing and transportatin for people living out of town.

If you have any solutions to these problems, please return my call.I need it badly.

Sincerely

Tina M Miller

Regards,

Tina Miller

2582 E Michigan St

Free Soil, MI 49411

Submitted on Friday, November 28, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because disabled and elderly individuals rely on these services for their health and wellbeing.

Regards,

Traci Phillips

10 E Chicago St

Coldwater, MI 49036

Submitted on Tuesday, December 2, 2025

Dear Members of the Special Committee on Aging,

Continued availability of Medicaid home and community-based services programs is important to me because they are essential to my daughter and son-in-law continuing to live independently in their own home. Both have worked in the past and receive Social Security Disability, Medicare, and Medicaid. My daughter, who is 58, was born with cerebral palsy and learning disabilities and in recent years has suffered from severe recurring depression. My son-in-law, age 57, also has learning disabilities, type 1 diabetes, and severe scoliosis. Despite this, he was able to drive and work in the food service industry until five years ago when the scoliosis resulted in spinal cord damage, causing considerable loss of feeling and coordination in his hands and legs. As a result, he and my daughter are now totally dependent on us and on in-home care through Medicaid HCBS for almost all of their everyday needs. My wife and I are 79 and 80 years old respectively and, although we are still involved in their lives on a daily basis, we could not begin to provide all

of the support they need to live independently and could not provide for their future care as we become less able to assist them. Medicaid HCBS are truly a lifeline for them and for us.

Regards,

Michael DuRussel

2716 Plymouth St

Midland, MI 48642

Submitted on Tuesday, December 2, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me as a person with Autism Spectrum disorder which is my primary diagnosis and Bipolar 2 disorder as my secondary diagnosis because I like so many of us with disabilities want to live and be apart of the community in which we live. By having the Home and community based services we get to live Independently with the right accomidations and be just as productive as other non disabled individuals and live a life full of promise and prosperity just like everyone else does. In an instituion people get locked away and never interact with non disabled people. In an institution people would sit around all day with nothing to do and not live life full of promise and prosperity and suffer with broken dreams. What kind of a life is that? Take my life for example I have never been in an institution myself but I have watched videos of people in institutions and I know just by watching the videos of people in institutions and I know that's not the kind of life I envisioned for myself or anyone to be in ever if they don't have to. So as I previously stated that my life wasn't in an institution. I went to school and went throught young 5s and Kindergarden then grades 1-12 just like everyone else without a disabilities did and was put into special education with Individual Education Plan(IEP). Going back to the school I did at times struggle but I still learned how to read and write at a young age and some of my classes were general education while others were done in special education or the resource room. When growing up my mom taught me and my brother both to be independant she taugh me basic skills to keep up a house so that when we got old enough we could live independently in our own places. The skills that she taught both of us is how to dusty and clean, and when we got old enough she taugh us how to wash dishes and go to the laundromat and how to organize and throw things away ect. Now thanks to my mother I'm now an independent indivdual living on my own in a two bedroom apartment without help from staff and living life to the best of my abilitiy. I do have some support like I do have a representative payee that helps me to budget out my money, a caseworker

throught my local mental health that is medicaid paid for helps with my paperwork for recertification for my apparement and Deparment of Health and Human Services, and my Medicaid and Medicare, Plus I practice Supported decision making and I do have a circle of support meeting that meets monthly to help discuss big goals like going to school, getting a driver's license, keeping up my health goals ect. In the past I have had job coaches to help me to get jobs and I used to be self employed from 2009 til 2022. I had a housekeepin g business where I went and cleaned houses and at the end a commericla building. In July of 2022 I left the self employment business and worked for the local chapter of the Arc Community Advocates who advocates for people with disabilities at the Ferderal level, the state level, and the local or regional level. So all my life I have been taught to be independent and without the home and community based services I wouldn't be able to continued to be living indepently. I would probaly not be employed, or have a representive payee to help me with paying my bills ect. These home community based services are the lifeline of keeping people with disabilities living Indendently. I also do volunteer advocacy work for the state and I have sit on many different boards as well. I currently sit on Self-advocates of Michigan(SAM) board of directors, I also serve on the National self-advocacy board called Self Advocates Becoming Empowered(SABE). None of this would be possible without the Home and Community Based Services or the Michigan Developmental Disabilities Council with the voulunteer self advocacy.

Regards,

Sarah Carmany

723 Duke Ln

Kalamazoo, MI 49008

Submitted on Thursday, December 4, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am retired living in social security with Diabetes. If I can’t get assistance I won’t be able to afford my insulin. I also gave a great granddaughter with severe cerebral palsy is her mother cannot receive HCBS they will become homeless and unable to get her the therapy’s she needs

Regards,

Beverly Spires

211 S Laird St

White Pigeon, MI 49099

Submitted on Saturday, December 6, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because five years ago a woman walked up to me at church. "Do you want to be my penpal," she asked, by which she meant did I want to be friends who had coffee dates and baked cookies and played card games and sat together in church and called each other and celebrated birthdays and gave gifts and bemoaned snow and celebrated summer. We've been "penpals" ever since. My friend is in her 50s, has an intellectual disability, and has no family that cares for her. Her home is in community living. Without community living, she would not have safety, dignity, or the simple daily companionship that contributes to her flourishing. Community living has changed her life, and she in turn has changed mine.

Regards,

Amber Beery

2580 S Thomas Rd

Saginaw, MI 48609

MINNESOTA

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Because I care!

Regards,

Raleigh Koritz

4505 Nathan Ln N Apt 313

Minneapolis, MN 55442

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am quadriplegic.

Regards,

Jolie Klarich

1601 Fern St S

Cambridge, MN 55008

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I need low income based housing and I want to be with my community and enjoy life with my community. I want to be independent as well.

Regards,

Melissa Kubiszewski

2240 Skillman Ave E

Saint Paul, MN 55109

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I was in an auto accident 30 years ago, which resulted in a C345 incomplete fracture of my spine! To date, I have had 42 procedures to assist me in the quality of life I have today. I still suffer from chronic nerve pain from my chin to the tip of my fingers and toes. The first 10 years I was medicated heavily with narcotics which did nothing to ease my pain, but kept me solely in the dark from reality. In the last 20 years since I experienced help from a rehab center to get rid of the narcotics within my system, my quality of life as a quadriplegic has been a struggle still. There is so much need for accessibility within my community, my state and throughout the nation. The ADA standards are not enforced and if you do not have a different ability, generally, you are not even aware of how inaccessible your community is. I serve on several local, state and

national boards to advocate for better accessibility. 10 years ago I also started my own nonprofit called Mobility Mania - Accessibility for All. I believe that it is every individual's right to have quality of life opportunities in spite of their age, ability, cultural difference, or financial status. It is vital to the survival of those of us who live life differently for legislators to do the right thing and enforce the ADA standards to their fullest and go beyond to make them friendly standards, as well. It is discriminatory for anyone to hold an event that is not capable of providing accessibility for mobility, visually, hearing impaired and cognitively challenged people.

Regards,

Myrna Peterson

2304 McKinney Lake Rd

Grand Rapids, MN 55744

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matgters to me because

Regards,

Richard Grimm

3440 Hennepin Ave S

Minneapolis, MN 55408

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because our daughter is disabled and she is currently living in an apartment. We are so grateful about the care she receives in the community. SNAP Benefits give her the much needed food that she needs daily. She is able to see doctors, specialists, therapists, go to appointments through Lyft and medical rides, and Social Security provides monthly payments so she can live in her apartment. We are very very grateful that she can do her best and enjoy her life with her benefits. Thank You.

Regards,

Kathleen Schaffenberger

4305 Orion Ln

Eagan, MN 55123

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my dear mentally handicapped brother lived in a RSI community based group home in Princeton MN. He was able to attend the local county fair, attend local airport annual pancake fund raiser, visit the local exercise facility, hike around the local parks with me or staff members. Some of the other residents worked at local businesses.

His life was a struggle but due to community based services he was a happy camper.

Thanks for your time and consideration.

Regards,

Susan Eisenbacher

Cambridge, MN 55008

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because housing is at Mega premium. Costs are astronomical!!! Older population are hit hardest, & require places to call home.

Regards,

Peggy Erickson

2805 E Lake St

Minneapolis, MN 55406

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I get to live my life the way I want to. Please don't change that. Thank you

Regards,

Chris Higgins

815 6th Ave NW

Rochester, MN 55901

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I work in a group home they have Medicaid if that gets cut they can't go appointments if need be or get there medications.

Regards,

Maryjo Bartos

1003 Washington St

Eveleth, MN 55734

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

being part of the community helps me feel less alone. I also feel that being in the community helps raise awareness on accessibility for everyone. Being able to stay home and part of the community helps me stay healthy. having access to HBCS Allows different options so I can say home and be part of the community. Each program has its place of importance. I feel like if you take away any piece it would be impossible for people with disabilities to live at home.

Regards,

Leon Saeland

5164 Willshar Way NW

Bemidji, MN 56601

Submitted on Friday, November 28, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have lived here all my life.

Regards,

Mary Wallin

Willmar, MN 56201

MISSISSIPPI

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I rely on it every day to live and work. Despite the fact that I'm 40-years old and can only barely move my fingers, I'm able to to live at home and work with a NASA contractor remotely. If not for my team of caregivers that I access thanks to HCBS programs, I'd end up in a nursing home, unable to work and pay taxes, while using even more taxpayer dollars.

These programs are essential. And we need federal access and eligibility. Right now I'm a prisoner to my state because my critical HCBS to not travel with me. In the modern world, where college is essential and good jobs sometimes require relocating, we need reliable, uninterrupted, nationwide access to these programs no matter where we happen be.

Regards,

Roy Watson

1843 Jayroe Dr

Byram, MS 39272

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Medicaid Home and Community-Based Services (HCBS) have helped me to live in the community and avoid a nursing home for about the last 25 years. Because of these services, I've been able to pursue a college education and a job. Without these services, I would not be able to contribute back to society by working and paying taxes, nor would I be involved in the community. This program affords me the opportunity not only to work and to contribute but also to attend church and other social functions, since I have a severe disability that confines me to a wheelchair, and I need assistance at all times from people who are trained to help me, including feeding me, repositioning me in my wheelchair, washing my face, and all other activities of daily living. As a 37 year old with a single mother who is almost 70, this is extremely important, as she would not be able to do it all on her own, especially considering that my brother has the same genetic condition and also relies on HCBS services.

Regards,

Thomas Watson

1843 Jayroe Dr

Byram, MS 39272

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because without assistance, so many individuals are left without the ability to see the doctors, have enough food, or even just have the dignity that is deserved by living indipendently. Please help.

Regards,

Susan Abdullah

902 MS-27

Tylertown, MS 39667

Submitted on Sunday, December 7, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my oldest son has Down Syndrome. He functions on a 5 to 6 year old level. He is able to have the support he needs to have a part time job, go shopping, participate in community activities and participate in a special needs bowling team.He doesn't have to depend on us for these activities.

He is employed as a baker and custodian at the Finest Grind Coffee Shop in Ocean Springs, Ms. Yes, he bakes. His job coach provides assistance with reading recipes, measuring and staying on task. He gets to meet new people and make friends. The best part of all this is that he doesn't have to have his mama and daddy with him all the time. He is very proud of what he can do and that he can earn a paycheck just like everyone else.

He will always need someone with him at home, in the community and at home. We will take care of him at home as long as we are able. However, since he is in his mid forties and we are in our mid seventies we know that he will need someone to be here for him in the future. He does have a younger brother who lives in another state who would try to care for him in the future, but this would require our son, Nathan to move there. Nathan would lose his Medicaid Waiver support. His younger brother is not in the financial position to provide the supports Nathan needs to continue function in society in a different state. There is currently a 12 year waiting list for the ID/DD Waiver in Mississippi. I have no idea what the waiting list is for Louisiana at this time.

Ideally, Nathan would be able to stay in his home in his community with support. He would need someone to be in the home with him when he's there. The group homes in our area are rather grim. Nursing homes and institutions are more expensive. He would lose privacy and independence without the support he gets from Medicaid ID/DD Waiver.

Regards,

Mary Gilly

3824 Riverpine Dr

Moss Point, MS 39563

MISSOURI

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because without Medicaid Home and Community Based Services I would be in a hospital. Being able to live at home with my mom means I can have a dog and it means I can have a job that I love, helping others with developmental disabilities. Everyone with a disability deserves to be a part of their community. Community living is less expensive than institutions, and it's the right thing to do.

Regards,

Nicole Noblet

2005 NE 78th St

Kansas City, MO 64118

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I had been receiving help with Home Health but was recently stopped because I became eligible for Medicare but I still have Medicaid. The home health care company stopped my services all together. I require 72 hours a month, 7 days a weeks, 3 hours a day and for the past 2 months I've not had a homemaker here to help me to eat, bathe, dress, move about the home. Someone needs to help me with this issue as being disabled I can't do it on my own.

Regards,

Paula Evans

Dexter, MO 63841

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am one of three registered and licensed dietitians and nutritionists in the state of Missouri who work explitly with people with intellectual and developmental disabilities. I have seen firsthand that having the nutrition services has increased the quality and enjoyment of their lives.

Regards,

Alysha Broughton

1005 St Brendan Ln

Florissant, MO 63031

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my 28 year old son with severe autism, static encephalopathy and epilepsy enjoys being around his peers. He loves his Adult Day Program where he participates in activities and volunteers with Meals on Wheels. The staff is amazing and it allows me to work as a substitute teacher. He's been going there since he aged out of school at 21 years old. We can't imagine what we would do without this service!

Regards,

Tracey Hermann

3263 State Hwy 47

Old Monroe, MO 63369

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my granddaughter has down syndrome so she will need some help from the Ark in Springfield mo please don't look past them look at them and let them know that they all matter to you and our community

Regards,

Carol kilburn

933 Megan Ln Apt A

Willard, MO 65781

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I had a sister who benefitted from these programs. She was mentally challenged. She went to a state school till she was 21. Then she worked at a workshop for people with disabilities till she was in her 50's. She also stared living in a group home when in her 40's. She really liked the group home & working at a workshop where she made some money. I think she had a pretty good life & she seemed happy. She passed away when she was 70. Without the help of Medicare & other programs this would not have been possible. This is a good idea for people with disabilities. I was her guardian so I was very aware of the benefits that she received. Thank you.

Regards,

Patricia Reed

738 Max Ave

O'fallon, MO 63366

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to I AM A SENIOR CITIZEN IM 70. I LIVE ON SS DISABILITY. I WAS FORCED TO BE DISABILITY. I HAVE MOBILITY ISSUES. HAD MANY MSNY SURGERIES ON MY HIPS BILATERAL N KNEES BILATERAL. I ALSO HAVE INSTINE ISSUES N GET BOWEL BLOCKAGES N HSVE TO MAKE MANY TRIPS TO THE HOSPITAL. I PAY MY RENT N BILLS. THEN I HAVE TO DECIDE ???? DO I BUY MY BABY (DOG) FOOD, OR MEDICATIONS

Regards,

Debra Barcus

2514 Aurora Ave

Maryville, MO 64468

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we all have to share this planet and the sooner we work together the better.

Regards,

Jane Markley

10576 Lanell Woods Rd

Festus, MO 63028

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

HCBS is an important to me because I am disabled, older, DeafBlind constituen of USA. PLease urge to support HCBS. That does helping and educating many things to quaifities of lives of us.

Regards,

Carolynsue Alflen

353 Caddo

Fair Grove, MO 65648

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a person with a severely-challenged immune system who has had to infuse donor antibodies weekly for about 15 years in order to stay alive. I am almost 60, and cannot imagine what it would be like to lose my disability. I have fought so hard to keep existing. Please fight for my right to live.

Regards,

Susan Stuart

Otto, MO 63052

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

“My 25th Re-Birthday — A Story of Falling, Faith, and Raising"

God has been carrying me for twenty-five years this month.

On September 29th, 2000, I left home as a single mom to go to work. In one instant my world changed. I fell twenty-five feet down an empty elevator shaft and landed on a concrete floor strewn with glass, cans, and debris.

When you meet me now you might think you know my story — you see a smile, a friendly face, a woman who tries to be warm and courteous. But on the inside I am very different than you might imagine. That fall did not just bruise and damage my body; it rearranged my life. It took my sense of certainty, it took pieces of the person I used to be, and it pressed me into a new form of living.

In the years that followed, I went through more than forty surgeries. Lost everything I worked so hard for. I faced pain and setbacks that most people never see. I now live with a frontal-lobe traumatic brain injury — a TBI — that has changed the way I think, feel, and do life. Many of my disabilities are invisible. You can’t always see the anxiety. You can’t always see the depression. You can’t always see how hard a simple decision can be when your brain is still relearning how to be your friend.

There were so many times I wanted to give up. When you suffer long enough, your soul grows weary — and I know that weary place. I was confused, scared, tired and lost for a very long time, and still have that feeling. I could not find the light through the darkness that surrounded me.

But my story is not only about the fall or the suffering. It is about what God did in the hole where I thought I would stay. It is about the hand that reached down and lifted me out. I had to drag myself out of that abyss time and time again. I had to relearn how to walk and talk at a Brain Injury center (St. Johns HIRC) for over a year and lived in Assistant Living for 7 years suffering more abuse, lost my children which was the worst, lost my home, almost everything I had, it wasn’t the suffering that defined me — it was the way I kept rising. That relentless, stubborn insistence to keep going, to keep growing, to keep believing — that is what formed me.

Scripture says in Isaiah 43:2, “When you pass through the waters, I will be with you; and when you walk through the fire, you will not be burned.” That promise became real to me. I walked through fires —been through over 40 surgeries, grief, and long dark nights — and I was not consumed. God carried me when I could not carry myself.

I didn’t become brave because I wanted to be brave. I became brave because there was no other option. God made me courageous out of necessity, and He made me more than the things that would have defeated me. I am not just a survivor; I am a warrior with an iron will and a passionate spirit. My scars are not signs of shame — they are maps of God’s mercy. They tell the story of battles fought and won through the strength He supplies.

There was a season I felt ashamed — ashamed that I had fallen, ashamed of being different, scared people would not accept me. But today I celebrate those differences. I celebrate my cracks because the light comes through them. I celebrate the invisible wounds because they show His handiwork in restoration. I will celebrate my 25th “rebirthday” today September 29th. The day I fell was the end of one life and the beginning of another — a life shaped by grace and sustained by God.

Romans 8:28 says, “And we know that for those who love God all things work together for good.” I cannot explain every painful detail, but I can say with my whole heart that God took what was meant for ruin and made a purpose. He has used my broken pieces to reflect His strength and His love.

So if you see me and think you know me — think again. Don’t measure me only by what is visible. Pray for me when I am weak. Walk beside the hurting. Speak gently to the ones whose struggles are hidden. And if anyone here is carrying a secret burden — whether it’s a physical wound, a broken heart, or a mind that is tired — know this: God sees you. He does not forget you. He can lift you out. He turned my fall into a rebirth.

Today when I celebrate my 25th rebirthday, I do not ask for pity. I only ask that my story point to the God who carried me, who heals in ways we sometimes don’t understand, and who gives us strength one day at a time.

My Closing Scripture & Prayer

Let us be reminded of Psalm 34:18 — “The Lord is close to the brokenhearted and saves those who are crushed in spirit.”

Dear Heavenly Father, I thank You for carrying me when I could not walk or talk. I thank You for every surgeon’s steady hand in over 40 surgeries, every prayer lifted on my behalf, and every small victory that proved Your faithfulness. Continue to use my life to point others to

You. Heal the hidden wounds in this room. Give strength to the weary and hope to the hopeless. In Jesus' name, Amen.

Regards,

Barbara Inman

2729 Kenny Dr

St. Louis, MO 63125

MONTANA

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a mother of a son with autism with learning disabilities. I have been my sons advocate for his diagnosis his whole life. After being diagnosed at 3 years of age, I was able to enroll my son into preschool with disabilities. Helping my son with these tools at early age was what I know now, was much needed. It helped my son navigate a world that was not made for him. He dealt with sensory issues and so we as a family with his pediatricians help put him into speech therapy. My son at that point in his life was non verbal. Then from there his speech therapist referred my son to OT therapy for eating disorder. My son's sensory issues was affecting his ability to eat. Without these tools my son would have had no help. Which would of left me with absolutely no help in this disability. With intense speech, and OT therapy this helped my son and myself through life. My son at age 5 spoke for the first time not just gibberish ..he said mom. With his sensory issues At 11 he started to eat meat finally and not just chicken nuggets. Without all these therapies and his IEP he is getting through life and understanding his autism. My son's sensory issues are still there but we have the tools to help him and he knows the tools also to help himself. He is 16 years now and he is finally reading.

At grade 5 in his IEP meeting we were told my son was never going to read. I have never felt so defeated in my life and left in tears. My son my have autism but I wasn't going to let it define him. I was then having a conversation with his special ed teacher and he said "let's try a new way of reading for JJ."

Memory!! We stopped phonics and tried using his memory on the shape of the word. It took two years but I did it! My son is reading has a little bit of a hard time sometimes…but he is reading! We are trying to teach him now how to write. Without all these tools in our lives would my son have gotten this far?

My goal for my son is that he learns to write and with the help of his IEP and his OT therapy we can meet that goal. My son is one of the smartest people I have ever known. His brain is just wired differently and that's all. I know my son will need help throughout his life. I had a conversation with his middle school teacher and I asked do you think my son will ever be able to live on his own…

She replied "no…I feel he will need help his whole life."

I asked her this because I, JJs mother was diagnosed with cancer and I have now progressed to stage 4. I'm doing better and have been taken off immunotherapy for 5 months. Only to see if the cancer was going to stay NED I will never be in remission. So I need to know that my son will be okay when and if I leave him early in life. I need to know my son will be okay on his own because without these services he will be dealing with this alone. I'm his caretaker and without OT therapy we were at a hard place. My son needed help toileting till 13. So his IEP and OT were my saving grace for me and JJ. These are all sensory issues that he deals with. He also deals with anxiety as all kids with autism do. This world has many sounds that almost feel like they almost physically hurt him.

Im proud to say my son is wearing just his hat and no noise canceling headphones; which he use to wear every minute of the day. With all these supports and tools he is learning, he is learning to live in this world.

His reading has been huge!! He is seeing a whole new world through the books he is reading. My goal is writing and with the help of OT and his IEP we will meet that goal even if it takes years. He will go to college with support,..this is my dream. I look back and wonder were we would be if we didn't have these services.

And as a grandmother I have a 5 year old grandson diagnosed with Autism. He is non verbal. This was his first year of school and he is saying words. I only hope these services will be available for him also in the future.

Regards,

Deidrie Leaf

Missoula, MT 59802

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because they are very important to me and help me out whenever I need it.

Regards,

Jeremy Brooks

1205 N 25th Ave

Bozeman, MT 59718

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

I have lived in a wonderful place, where I own my home, for 35 years. It is quiet here and I can see the stars at night. It's a ghost town - there are no stores, no public transportation, no local services. I'm getting older, and trying to figure out how to find someone to help my household on a regular basis. Social security is not generous, so I can't offer much pay. I'm hoping I can mentor, and offer room and board to someone who wants to live in an isolated quiet place.

Regards,

K.G.H. Nicholes

MT 59053

NEBRASKA

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a son who needs these services, please continue to help the one who can not help them self's

Regards,

william mathies

38375 Rd 711

Mccook, NE 69001

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because everyone deserves to live a full life no matter who you are.

Regards,

Donna Hauck

2603 Circle Dr

Scottsbluff, NE 69361

NEVADA

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me becauseit is the right thing to do, to care for those, who cannot care for themselves...

Regards,

GREGORY PAVLIDIS

312 Carole Little Ct

Henderson, NV 89014

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because It takes care/helps, of ALL the people who live there!

Regards,

Charlene Boydston Boydston

3951 W Donner St

Pahrump, NV 89048

NEW HAMPSHIRE

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

I know people who've been affected badly, by no access to SNAP & the Medicaid Cuts have left so many without enough coverage for healthcare they need to keep going--in these horrific presidential rulings.

Regards,

Linda Ferland

43 Pearl St

Claremont, NH 03743

NEW JERSEY

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it keeps people like myself healthy and happy.

Regards,

Derek Binelli

Linden, NJ 07036

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because everyone

needs a home

Regards,

Ed Adams

317 Texas Ave

Monroe, NJ 08094

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because they need to live a life like we do and have ample resources to assist them

Regards,

Dylbere Qiku

651 Bound Brook Rd

Middlesex, NJ 08846

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because these people have enough problems without taking things away from them that makes their life a little easier.

Regards,

Jo Remster

150 Salem Woodstown Rd

Mannington Township, NJ 08079

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Dear Members of the Senate Special Committee on Aging,

My name is Amanda Nehme. I live in East Brunswick, New Jersey, and I am the mother of a four-year-old daughter, Charlee, who lives with Dravet syndrome (a catastrophic genetic epilepsy), autism spectrum disorder, and global developmental delays. She is nonverbal, has multiple seizure types, significant behavioral and safety challenges, and requires constant supervision and skilled medical support to stay safe at home and in the community.

For our family, Medicaid home and community-based services (HCBS) are the difference between Charlee growing up in her home with her parents and little brother—or being pushed toward institutional care or repeated hospitalizations.

How Medicaid HCBS impact our daily life

Charlee's seizures are frequent, unpredictable, and can become life-threatening within minutes. She has had status seizures, turning blue and requiring emergency rescue medication to stop them. Some have happened during everyday activities like a bath. Even moderately warm water, a mild illness, or excitement can trigger a dangerous event. She needs someone watching her at all times who understands her rescue plan and can act immediately.

Medicaid HCBS touch nearly every part of our daily life:

Skilled nursing and medical oversight at home and in the community. When Charlee's in-home nursing hours are authorized, a nurse can monitor her seizures, manage her complex medication schedule, and recognize early warning signs before an emergency spirals out of control. That support keeps her out of the hospital and allows us to manage life-threatening epilepsy in our living room instead of an ICU.

Access to a pediatric medical day program in early childhood instead of institutional care. When Charlee was under three years old, she attended a pediatric medical day care program that integrated nursing, therapies, and early education. This program only accepted Medicaid. There, she received physical, occupational, and speech therapy in a setting built around children with complex medical needs, rather than a traditional childcare setting that could not safely manage her seizures or behaviors. HCBS funding is what made that community-based option possible during a critical developmental window,

instead of pushing us toward long-term care or constant hospitalization. At age three, she transitioned into a preschool program, but she still needs Medicaid HCBS to make her participation safe and sustainable.

Early intervention and intensive therapies. Because of Medicaid, Charlee has had early intervention services and therapies aimed at communication, motor skills, and adaptive behavior. These are not “extras” for her—they are the tools that help her learn to participate, in whatever way she can, in family life, school, and eventually the broader community.

The ability for our family to remain economically and emotionally stable. I work full-time, and our family of four already relies heavily on my employer insurance for much of Charlee’s care. But even with private insurance, her care is extraordinarily expensive and does not fully cover skilled nursing, medical programs, or the level of therapies she requires. Medicaid HCBS fills those gaps. Without it, the costs of her care would quickly overwhelm us, forcing impossible choices between her medical needs and basic expenses like housing and food.

In short, Medicaid HCBS allow Charlee to live at home, attend appropriate community-based programs, receive therapies, and be safely cared for by a combination of professionals and her family, rather than being separated from us.

What would happen if we didn’t have Medicaid HCBS

We had a glimpse of that future when Charlee’s Medicaid eligibility was threatened because our household income was deemed too high, despite the fact that her medical costs vastly exceed anything a typical family can absorb. Losing or reducing Medicaid HCBS would not simply be a paperwork change for us—it would dismantle the supports that keep our daughter alive and with us.

Without Medicaid HCBS:

Charlee would be at much higher risk of preventable emergencies and death. Dravet syndrome carries a high risk of status epilepticus and Sudden Unexpected Death in Epilepsy (SUDEP). Charlee has already had prolonged seizures that required emergency medication and urgent intervention. Removing in-home and program-based nursing means more 911 calls, more ICU admissions, and a greater chance that a seizure will be the one we cannot stop in time.

She would likely lose access to the types of medically appropriate programs she needs. Programs that can safely support children with complex medical needs typically rely on Medicaid. Without HCBS, she would either be pushed into settings that cannot safely

manage her seizures and behaviors, or lose access altogether, leaving us with no realistic community-based options.

One of us would be forced out of the workforce, and we still could not provide the same level of care. If Medicaid HCBS were taken away, I would almost certainly have to leave my job to try to fill the gap in supervision and care. Even then, I am not a nurse. I cannot replace skilled nursing, nor can I safely manage constant 24/7 care alone without burning out or risking mistakes. We would lose income and employer coverage at the exact moment our out-of-pocket costs skyrocketed.

The “choice” would shift from community living to institutionalization or repeated crisis care. Without HCBS, families like mine do not actually have viable options. The realistic outcomes are: a child in a nursing facility, a revolving door of ER visits and hospital stays, or a family collapsing under financial and caregiving strain. None of these paths preserve dignity, independence, or community connection—not for the person with a disability, and not for their siblings or parents.

Charlee’s developmental potential would shrink. Therapies, consistent routines, and safe exposure to the world are what allow her to make gains, however small. If the focus shifts from “How can we help her engage?” to “How do we keep her alive with fewer supports?”, her world—and ours—narrows dramatically.

Why community living matters for us

When HCBS are in place, Charlee is not just “a medically complex child.” She is a little sister who squeals when she sees her brother, a daughter who reaches for us, a student in a community-based program, and a member of our New Jersey community. At night, she co-sleeps with us because it is not safe for her to sleep alone. We monitor her breathing and movements, knowing that a seizure can happen at any time. We eat together at our kitchen table. We celebrate small victories at home—an extra step, a new sign, a calmer transition. These are the ordinary moments that any family takes for granted, made possible for us only because Medicaid HCBS keep her safe enough to live outside an institution.

I am asking you to protect and strengthen Medicaid HCBS—not only for older adults, but for children like my daughter who will rely on these supports across their entire lives. Policies that cap or narrow access based purely on parental income, without accounting for the extraordinary cost and intensity of care, effectively punish families for trying to work while raising a medically fragile child. We need a system that recognizes that HCBS are not optional—they are foundational infrastructure that keeps disabled people in their homes, their schools, and their communities.

Thank you for considering our family's story and for holding this hearing. I hope you will look at Medicaid HCBS not as a line item, but as the reason families like mine can keep our children safe, together, and truly part of our communities.

Sincerely,

Amanda Nehme

East Brunswick, New Jersey

Regards,

Amanda Nehme

715 Cranbury Cir

East Brunswick, NJ 08816

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, I had a stroke years ago and I have a lot of medical issues, I rely on Medicaid for my meds, because without my meds I wouldn't be able to survive, I also rely on Medicaid because they pay for my home health care and my transportation to and from my doctors appointments, without Medicaid I'd be lost. Please keep Medicaid open for people like me who can't afford healthcare and rely on Medicaid, thank you

Regards,

Tonya Singleton

1460 Parkside Ave Apt 516

Ewing, NJ 08638

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because people who have a disability or an invisible disability need Medicaid assistance to provide them a normal life they deserve and not get judged for being different. It breaks my heart when the Republicans voted to cut Medicaid.

Because in my home state of New Jersey has 30 to 50 assistance programs for people with a disability or an invisible disability. Especially kids who are suffering from these disabilities since childhood. That's the reason why community living matters most.

Regards,

Jaszmene Smith

1017 School Ln

Bridgeton, NJ 08302

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

These services are essentials for families with disabilities like mine.

Having services where people come to our home is the most comfortable.

Early intervention was super important for my son. They helped us figure out a way to get an autism diagnosis which is nearly impossible in the state of NJ.

Regards,

Jacob Earwood

226 Dorchester Dr

East Windsor, NJ 08512

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a physical therapist and treat patients with all kinds of disabilities and injuries and believe everyone deserves equal care to live the life they love.

Regards,

Michelle Carlin

150 W Cedar Ave Apt 2C

Somers Point, NJ 08244

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, we (husband and son with a disability are able to still live in our community. We have wonderful neighbors that he is familiar with him and care about his safety. My adult son attends a day program thank provides activities and care for my adult son that needs 24/ 7 care. That program assist with various areas of support to still be able to live in the community . And he is able to attend and worship in mass with us.

Thanks for the support,

Regards,

Susana Medina

2828 Arthur Ave

Camden, NJ 08105

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Home snd community resources are so valuable to disabled individuals sa d those who are aging. We all know someone who needs these services.

Regards,

Barbara Gainsford

6 Ray Smith Rd

Gloucester Township, NJ 08081

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

I would like to have some subsidies for the purchase of a van to transport me for medical reasons. If I were to use a handicap transport.every time and applied for insurance coverage it would be a lot of money. I have my own van I am paying on and it's making it tight to live on. My van needs $2000 worth of repairs, which I can't afford now.

Regards,

David Owens

56 N Myrtle St

Vineland, NJ 08360

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps me and others who really need it, I need help with my house and I'm my community there is no money too help me fix my house, we really need your help too save our homes and too help people like me with disability! Thank You for your Time! Sarah Adam

Regards,

Sarah Adam

198 Mercer St

Phillipsburg, NJ 08865

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

My oldest son is 25 years old and has Down syndrome, autism & a seizure disorder. Community living is important to us because we rely on Medicaid and the associated programs to help facilitate his independence and community inclusion. While he doesn't live the typical life of a typical 25 year old, we do our best to build a program and schedule with his Medicaid funding that provides enriching activities, community outings, social interactions, therapeutic activities and more. He is not capable of doing any of these things independently so without the support of Medicaid funding we would not be able to provide him the supports to be successful in the community. The cost to keep him in the

community is much less than the cost of placing him in a group home and the quality of life is so much better when he can live in his community with his family. Please continue to support individuals with disabilities and help them maintain the dignified life of living in the community.

Regards,

Pamela Ginet

719 3rd St

Ocean City, NJ 08226

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because.

Regards,

Carl Major

1448 Boxwood Dr

Gloucester Township, NJ 08012

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because living in a loving home is essential for this population. They are in a caring, well-maintained environment. Living in a group home can sometimes be unsafe, unhealthy, and lonely.

More pay, better training, and cameras may resolve thisissue

Regards,

Marisa Anderson

735 Darlington Dr

Old Bridge, NJ 08857

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

If I don't have the services that receive then I can't attend day program's which I really enjoy doing. I don't want to lose my programs or my friends from the programs please don't the services away

Regards,

Jessica Letts

415 Durand Rd

Neptune City, NJ 07753

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

People with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. HCBS help make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.

Regards,

Madeleine Lee

59 Michael Dr

Westfield, NJ 07090

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we need our government to step up and take care of our Country and all the people in it struggling every day to survive. LETS MAKE AMERICA GREAT AGAIN!!!

Regards,

Raffaella Selvaggio

288 Alden St

Wallington, NJ 07057

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I like being a decent person.

Regards,

Ann Sandritter

3 Ashwood Mall Apt B

Old Bridge, NJ 08857

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because having a diverse population creates opportunities for growth for the disabled and non disabled alike. People with disabilities need access to resources and experiences that enrich their lives. Those of us fortunate enough to not experience a disability are able to interact with and develop empathy for people with differing abilities.

"You ultimately judge the civility of a society not by how it treats the rich, the powerful... but by how it treats the poor, the disfavored and the disadvantaged," Bryan Stevenson.

Do what's right. Save lives by saving Medicaid and HCBS.

Regards,

Lori Leopardi

4 Middleton Ave

Ewing Township, NJ 08628

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps each other get through this cold world. We're all here for each other

Regards,

Robert Albert

4070 Asbury Ave

Tinton Falls, NJ 07753

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

Please help us

Regards,

Sister Miller

54 Chester Ave

Newark, NJ 07104

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son James is 33 and We pray everyday that congress will help us with a different situation when it comes to living independently.It takes a village.I think the reality of the world congress or anyone else doesn't no until it becomes your everyday life.I would be most grateful If I am able to tell how are needs can not be met.James , 3 years ago asked for help for counseling through DDD I got it for him.My case manager,and The Phycologist and myself are still shocked never got a call for him to be heard..I know that is suppose too be a happy letter.I think in reality housing need another level for some like James.Looking foward for the right person to get to me.Thank You Mary Ann Farley.

Regards,

Mary Farley

19 Shelley Rd

Springfield, NJ 07081

Submitted on Friday, December 5, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son can live in a supervised apartment with two other young men with disabilities. It is critical that he has housing and care because his parents are elderly and he has no other family. He also benefits from job training and placement services.

Regards,

Sandy Smith

1 Monroe Ave

Lawrence Township, NJ 08648

NEW MEXICO

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a parent with advancing dementia and she needs care that her older children--who are all senior citizens--cannot provide because they all work full time. Currently my mother is receiving check-ins from a hospice nurse a few times a week, and, while this helps, it's not nearly enough. Congress, who is richly compensated by the American people, has failed miserably so far by taking care of us in return. So many of us are struggling just to get by. We see the hypocrisy and our tax dollars will eventually run out if Congress does not correct their current, oligarchic course.

Regards,

Halli Bourne

222 Morningside Dr SE

Albuquerque, NM 87108

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we need to be able to stay in our own homes and have access to good food and healthcare facilities.

Regards,

Maresa Pryor-Luzier

30 Yucca Cir

Datil, NM 87821

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it is important to feel welcomed and not a burden to anyone!

Regards,

Jessica Castillo

NM 87114

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because all humans deserve a chance to thrive. When we include our special brothers and sisters, we fulfill our obligations as a civilized and caring society. If resources are taken from families with special needs citizens their lives will most likely become stressful and unmanageable thereby creating a decline in several families' mental health and well-being. Remember the people, Congress. It is us who pay your wages to serve the greater good of this country.

Regards,

Laura Vickers

Farmington, NM 87401

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities need our community.

Regards,

Chemen Ochoa

1 Altura Dr

Santa Fe, NM 87508

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because It does.

Regards,

I. Engle

605 Bosque St

Tularosa, NM 88352

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Medicaid's Home and Community Based Living allows my daughter—30, intellectually disabled—to have a rich social life, volunteer in her community, participate in sports, and hold a part-time job where she's been honored as an outstanding employee! All of these things enrich her life and ours, and give her the independence and confidence that all of us

need as humans in the world. So many of these things would be diminished or unduly complicated or nonexistent for our family without Medicaid's HCBS program.

Regards,

Tonya Iseminger

793 Tramway Ln NE Unit G

Albuquerque, NM 87122

NEW YORK

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps everyone, especially those who are in need.

Regards,

christina scott

1814 Michigan Ave

Niagara Falls, NY 14305

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me becaus

Regards,

Gordon Wood

180 Webster St Apt 104

Malone, NY 12953

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I want to be part of the mainstream.

Regards,

Meredith Kent-Berman

235 E 22nd St Apt 12E

New York, NY 10010

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

I have an adult brother with special needs.

I work at an agency that serves adults with special needs. We are not allotted enough funding to better serve our aging population.

Our population gets excellent care we need more funding for wheelchair accessible facilities for our aging population.

Regards,

esther fischer

1857 E 13th St

Brooklyn, NY 11229

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

I support disabilities

Regards,

Anthony chobot

Queens, NY 11385

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son is disabled and I need to know that he will be able to continue living with help in a safe environment.

Regards,

Len Carella

2418 Pearsall Ave

NY 10469

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. Programs like Medicaid home and community-based services (HCBS) help make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.

Regards,

Thyais Brown-Newball

480 Lefferts Ave

NY 11225

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I see the positive impact on people's lives. In our community people with disabilities provide volunteering and support to the community and without funding these supports would not be possible.

Regards,

elizabeth rowntree

149 Cherry Ave Apt B

Delmar, NY 12054

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because as a Direct Service Provider the individuals that we serve directly benefit from the funding provided by HCBS. In fact the services provided by the funds would cease to exist. Thousands of Direct Service Providers rely on HCBS funds to provide services to a severely underserved population of Americans.

Regards,

Michael Muscaro

16 Inter Wy

Purdys, NY 10578

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because i want to help people with disabilities

Regards,

Shaeril McBrown

2914 Tenbroeck Ave

NY 10469

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I do not want to be in a home. Just my home

Regards,

Mary Gembecki

28 Foxwood Dr

Pleasantville, NY 10570

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters because it reminds us that we are not alone—we grow, heal, and thrive when we have people around us who care. It also creates a sense of belonging and support that strengthens everyone involved.

Regards,

CAMARA FOSTER

226 E 5th St

Mt Vernon, NY 10553

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it's my right to be able to live like everyone else! There is a difference between disabled and handicapped, for me living in a group home made me handicap. I couldn't live the life of my choice but now living in the community I'm not handicapped I am, thriving with a disability. Community living is the difference between simply living and thriving !

Regards,

Letisia Comstock-Allcorn

120 N Warner St

Oneida, NY 13421

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a niece who is in her 40's who is living with Cerebral Palsy. Although she is high functioning she is not able to do certain things on her

own. She can be easily taken advantage of. The programs that are currently available she needs in order to be part of the community and at the same time have people who can support and advocate for her where she cannot. I also work as a DSP in a residential program. If it weren't for the funds received from Medicaid the ladies I support would probably be home bound most of the time. But with our help they go out nearly every day and have lives outside of their home. If I weren't able to work in this field and help support people with disabilities it would impact me emotionally because these ladies have become my extended family. Their joy is my joy. Helping out a smile on their face will put a smile on my face. To me there is no greater joy than to help a person achieve their happiness. Without the help of Medicaid it wouldn't be possible.

Regards,

Elyse Montalvo

2811 Kane Ave

Medford, NY 11763

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because everyone deserves to be able to live as independently as possible.

Regards,

Katie Bilow

231 New York Rd

Plattsburgh, NY 12903

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my dear sister has been living in a group home since just before my parents died. They spent their long lives advocating for the community and now as siblings, so are we. Our sister was born with a genetic disorder that rendered

her severely impaired from about the age 12. I recall her earlier, more neurotypical days with a

bittersweet mixture of nostalgia and sadness. Ever since she was in her 20s, our sister has lived in a group home sponsored by Aspire of Western New York. She is nearing 79 years old. We are aging too but we remain dedicated to her care inasmuch as we are physically and financially able to be. Without Medicaid and Aspire we would be lost. Please affirm and support those among us who are in such great need of government assistance. Be truly ProLife for the living.

Regards,

Judith Miller

16 Travis Blvd

Catskill, NY 12414

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Medicaid Home and Community-Based Services (HCBS) strengthen entire neighborhoods, including my own, because they let children with medical, developmental, or behavioral needs stay safely at home, remain engaged in school and community activities, and reduce the strain on families who might otherwise face crises or institutional placement. When families receive supports like respite, home nursing, behavioral services, and care coordination, parents are better able to work, siblings are more stable, and households remain economically and emotionally resilient. That stability ripples outward: schools experience fewer disruptions, local health systems face less emergency use, community organizations can collaborate more effectively, and neighbors benefit from a more inclusive, connected environment. In other words, HCBS doesn’t only help the families receiving services—it helps the whole neighborhood function with greater safety, cohesion, and opportunity. I love my neighborhood, and I want it to be resilient and functional. HCBS does that. If you're thinking of gutting these services you better have a freakin' awesome replacement lined up.

Regards,

Annie Brinich

58 Argyle Rd Apt 1B

Brooklyn, NY 11218

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

i want my food stamps

Regards,

DANIELLE RECTOR

26 2nd Ave

Gloversville, NY 12078

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have worked in this field for over 30 years and have the impact people with disabilities have in their communities. Promoting independence and making connections is important for all people to grow.

Regards,

Veronica Dona

19 W 11th Ave

Gloversville, NY 12078

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because every citizen deserves equal treatment and health care.

Regards,

Linda Jakubik

165 Lake St

Perry, NY 14530

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because one day I want to tell my story about how I live in my own apartment and receiving community habilitation

Regards,

Ryan Ford

525 Clove Rd

NY 10310

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we have many in our community who work and receive Medicaid. Losing these programs would be devastating.

Regards,

Thomas Pintagro

2200 Foote Avenue Ext

Jamestown, NY 14701

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community

living matters to me because l have worked all my life and had a husband that went on hospice for a couple of months. Time off then I had to strokes and can not work any longer. I receive $1041. Month.

There are a lot of people out there that have disabilities that can't work that need help with SSI

Regards,

Marjorie Pattison

6108 Loomis Rd

Farmington, NY 14425

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I support individuals with disabilities to find jobs. This allows for more independence in their lives!

Regards,

Anne Tulowitzki

82 Fairways Blvd

Buffalo, NY 14221

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have been working in this field for 14 years, alongside people with developmental disabilities who feel pride in living in a home of their own. Our agency supports the person with choice of where they want to live. Having the independence and autonomy to live your life the way you want to is important and many people without a disability take it for granted. Without the support from the funding for HCBS Medicaid waiver programs, many of the people we support would be homeless, hungry, and in unsafe situations. Many have no family that will help when times get tough. Fund these programs! People with DD deserve to have opportunities to grow, thrive and feel pride in their homes.

Regards,

Melissa Hiam

2495 Main St

Buffalo, NY 14214

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me. I have an adult son with disabilities and am very active in the community of people with disabilities, with the right supports they are valuable members of their communities making meaningful contributions. The community is also important in their lives. My son has a barber, a pizza guy, a kung fu master, a nail salon - he routinely visits these businesses. They know him and he supports them.

Regards,

Claudia Coen

40 High St

Geneva, NY 14456

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have 3 disabled young children and when they are grown having a community that serves their unique needs is a must. They need support emotionally, physically and mentally from a community that understands them. As well as a social community that they can find luke minded people in and enjoy activities with.

Regards,

Kim Delplato

344 Middle Rd

Caledonia, NY 14423

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a 12-year-old grandson who is medically fragile, special needs. Without Medicaid resources, we would not be able to keep him in our home. The medical supplies, medications, people who support him in all aspects, he would fail and we would as well. Zeke has a very rare form of epilepsy which is drug resistant. He's had thousands of seizures, numerous hospital stays, ambulance rides, currently takes seven different anti seizure medications. His seizures are still not controlled. He has a VNS system in place, feeding tube, medical Port as he gets phlebitis often. My daughter, his mother and his little brother Henry live with us. After she and Zeke's father divorced, she was struggling trying to take care of both boys with all of Zeke's medical needs on her own. Medicaid is the only way this works. He needs to be home and surrounded by people in his community/school who understand his health risks, and his learning disabilities. We are so grateful and fortunate for all the benefits he receives. With no end to his many medical difficulties in sight, it's the only way we see a future for him. As he ages out of school, the programs and assistance that will help our family and Zeke survive will be beneficial.

Regards,

Kelli Baker

129 Hubbell St

Canandaigua, NY 14424

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because To Whom It May Concern,

As an in-home childcare provider and community caregiver in the City of Buffalo, programs like Medicaid Home and Community-Based Services (HCBS) have a direct and meaningful impact on both my life and the children and families I serve. HCBS supports allow individuals children, adults, and seniors to receive essential care within their own homes and communities rather than in institutions. For families I work with, this means their loved ones can maintain stability, comfort, and dignity while still receiving the supports they need to thrive.

These services also affect me personally as a provider. Many of the children in my care come from families facing medical, developmental, emotional, or financial challenges. HCBS often fills the gap by ensuring families have access to medical equipment,

behavioral supports, therapies, and home-based assistance that I alone cannot provide. When families receive these supports, it strengthens their ability to maintain consistent childcare, employment, and overall household stability. It allows me, as a provider, to deliver safe, quality, and individualized care without being overwhelmed by unmet needs that fall outside of a daycare's role.

Regards,

Alicia Johnson

376 Florida St

Buffalo, NY 14208

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

My young adult son has an intellectual disability and autism. He is 24 and is living a fulfilling life due to the support he receives from Medicaid HBCS. Philip has received job training in the community, job coaching in the community, participates in the local YMCA, local riding programs, recreation programs and a day program. He would likely be doing none of these things if it weren't for Medicaid HBCS. He would be sitting in the house alone. My husband and I both work full time. His siblings are all either in college or working and living on their own, Philip would be sitting in the house staring at the walls. That would dissolve into depression and accompanying poor behavioral control. We've been there before and we don't want to go back to those days in and out of the hosptials.

Now he has a full life. He has friends, a community, a social life, and he is working towards a work life. He has commitments that get him up and out most days of the week. His comhab worker brings him into the community daily and he has built relationships with the neighborhood shop owners and local people. Philip is happy and contributing to society. I really don't know where we would be without his services. Philip is funny, loving, and kind, and he deserves to have days that are fulfilling and engaged with the community. This weekend, he will go to see a local theater with a recreation group That's adulting! He has all of this because of Medicaid HBCS.

Regards,

Jennifer Divalentino

20 Pleasant Ridge Rd

Harrison, NY 10528

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because as a senior I have lived with a disability since I was six months old. I have counted on have have received help and love from the many communities I have lived in all my life, making my life more rich

Regards,

Patricia Altro

4043 Cortina Rd

Baldwinsville, NY 13027

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because as someone who works people with special needs and disabilities, I see firsthand, the importance of independent living and having connections to their communities.

Regards,

Therbie Galliotte

84-19 Lander St

NY 11435

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because people with intellectual disabilities deserve to live independent and having services through Medicaid teach them the skills they need to be independent.

Regards,

Anita Smith

150 Van Buren St

Newark, NY 14513

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm disabled so to are my children. We depend upon services that are community based and understanding of our needs. We fear changing access or restrictions to it. Will make life that is already difficult, even more so. Please consider humans like us who have needs, hopes, dreams and aspirations in your heart and soul when you approach this matter.

Regards,

Daniel Fuller

Jamestown, NY 14701

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities did T ask for their disabilities. Therefore, they have every right to get the same benefits and accommodations that any one else deserves to get just as well.

Regards,

Alec Thorp

207 Friends Rd

Yorktown Heights, NY 10598

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my Autistic son receives HCBS. These services allow him to remain integrated into our community, providing community habilitation which teaches him how to live independently. It also allows him the opportunity to take community classes and learn alongside his peers, strenghtening relationships and learning real world skills.

If this were to be taken away, he would be more isolated and less independent. He would not contribute to society like his typical peers. His lack of independence would lead to tragic outcomes when his family are no longer around to care for him.

Please preserve this critical funding for Medicaid HCBS.

Regards,

Deborah Lombardi-Aiello

6 Oakmont Ct

Wading River, NY 11792

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because everyone needs to be part o a community (nit just a family). Withoout assistance the member of my family would not be able to participate and feel like she is able to help others too. The member of my family would be at home sitting in a chair. With help she is able to be a happy person who is able to feel the value of her life.

Regards,

Deborah Kair

33 Fieldstone Dr Apt C1

Hartsdale, NY 10530

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because of my 28 year old son. He is autistic, and lives in a group home. I am getting older, and I worry about his future. I can only hope that people with IDD, will continue to receive the assistance they need to be participating in community life. They deserve to have meaningful and productive lives. Thank you.

Regards,

Loraine Percoco

22 Floral Park St

Islip Terrace, NY 11752

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities and older adults deserve to live with independence, dignity, and connection to their communities.

Regards,

Elizabeth Schwartz

21-36 33rd Rd

NY 11106

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am 71 years old. There are very few resources up here for people needing services and the poverty level is so low that people luke me fall between the cracks.

I need to get ibto a pool, but all of the pools except for a tiny infinity pool at a hospital aren't accessible for people with mobility issues and they are not heated properly for older people like myself with joint propblems.

There is another pool over an hour away and while it is ARC, it is small and if I need to do laps along with excercise, only half is deep enough for me to do that. So, places like Clarkson or SUNY Potsdam or several other places need to get with the program and heat

these pools up and indtand of some of these crazy plastic contraptions, they need to have stairs with handrails that they cannpull up for swim team and put them down at other times. This was done at the Y in Taunton, MA and the Agricuktural College in Randolph, VT. It can be done. The other problem is proximitry to the regular gym facilities. At Clarkson, it's a bit of a hike. I understand fully well the difference from being young and my mum insisting that I get out of freezing cold water, which didn't bother me at all. I was very active, but then juries occur, life happens and this becomes tough.

I bought a house with a pond and I was lied to about everything. It was very polluted from the neighbors horses using it. I endedbupngetting pretty sick from E. Coli and there were children using it. So I researched and found a product I could get the pond cleaned up so that I wouldn't have to report them. Once in the water, I swim like I was young as long as it isb't freezibg out and this pond was so clean, it was coming back to life. Even had a couple of brook trout in it. I also told them that if they planned on letting the kids from tgeir summer horse program come over, give us a ring and one of us would assume lifeguard duties. I already have saved seceral kids from drowning at the St. Regis zRiver public beach. I know that people don't get their kids to Red Cross swimming lessons and either they can't swim or they don't do it very well. Understatement.

Then there is the problem of getting a decent detentist. I had to wait to get anotger appointment. I am a cardiac, pulmonary and kidney patient so having a bad tooth or needing deep cleaning and now anotger tooth is splitting and loosening. Anything like this causes problems with sinuses and then the infectiin can go to lungs or heart. This is very common and many people end up with no teeth and if tgey are lucky. They get poorly fitting dentures which can cause all sorts of problems. I don't know about you, but I don't particularly want a mechanical soft diet. They are inedible, overcooked and bland. Even the dog will walk away.

I worked in almost every discipline as an RN and ended up as an RN home health case manager. It was demanding, I could use my talents and was a very strong advocat for my patients. I made a difference in tgeir lives. I have watched as people got denied bmservices that any fool could see that they needed and the abuses by the systems put into place to protect them failed muserably. In one state, I had several people that needed either to be placed or needed better housing. One was actually cobdemned by the Board of Health only to be told that the elderly person could stay. She was veing manipulated financially by another relative, while the ones who found her in this state were the ones that were trying to help her. The problem was a !0 y.o. dog that was using her and every place as its toilet. No running water except for a rusted pipe in the kutchen, mouse and rat nests everywhere. They had repaired the furnace that had died sometime during the winter. She was a horder.

They found dead cats upstairs, the ceiling was leaking. Antique wallpaper with green which they used arsenic to make and the final problem? Asbestos. The air quality was so bad in there that I had to finish the interview outside. We had tried to get her the help that she needed onto to be told by the state it was her decision and it was clear that she coukdn't takr care of herself and while I loved animals, and I know how much she loved that dog, whatecer his issue, he couldb't be housebroken. She certainly couldn't take him for walks snd normal dog vehavior is they don't use the person as their personal potty. Tgen there was a man who had a whole in his floor of his trailer and plumbing problems. Couldn't take a shower or get washed up in tye bathroom. Actually, he needed a new trailer. I nearly fell through that floor when using the kitchen sink to wash my hands. It was that rotted. Then there was a couple who were denied because the social worker didn't use whole dollar amounts. They were $5 over the limit and services denied. I'm sorry, but $5? I had runins with the VAMC on a regular basis. I was really good at my job. I did it well. Really well. I just shook my head at their inability to understand the serious concerns. It's everywhere. Just before MA decided to carve up MA into different sections ecery provider save one exited my area. That one had 2000 patients. I had to put it in writing a request to keep my primary of 20 ,years who eas in a town not covered. Some hospitals refused patients to be cared for because they didn't have the right insurance.

When big corporations buy up all of the hospitals and VNAs in a particular area and protocols supercede commobsense and individual careplans, the hospitals take off older cobtrolled substances and BigbPharm and ibsurance companies are saying what a person can and cannot do, it's a major problem. I have literally been killed twice, nearly 5 other times and as an RN, retired or not, I know what is right and what is wrong. I had a massive lower GI bleed caused bybover heperization. Hospital policy said heoarin in belly. I was already on plavix and ASA, 81mg. I wasn't bedbound at that point, but I was once that blood came pouring out. I had protested because a heparin solution for IV's and the old SASH metged is used and i have lousy venoys access. They didn't have thatvproticol anymore vecause of heparinized PICC lines. Well, a short line or a midline or a central lind isn't a heparibized PICC line. The others need that. Then I required 4 blood transfusions. All were done incorrectly. They were supposed to have a fiktered IV drip in case of clits. Two RN's have to hang the blood togetger to make sure that it is the correct blood for the patient. Transfusion reactions are very serious.

At one hosputal stay, this clearly mentally challenged patiebt was in the hallway clearly upset. I went out and spoke to him. He settled down. All he needed was that. Another hospitaluzation, I was seriously abused and from the sound of things it was rampantbon that floor. There are laws regarding the prescription of anti-psychotics. A damned PA cannot write the order. It has to be a board certified psychiatrist in good standing in the

state. Mental status checks have to be performed. Now we get to people with pain. I perfer and want somebody who will do everything as far as regulsr care and that. More habds in the pot, more likelt somethingvwill happen. I have a leaky TAVR. No real clinucian will order 5-6 weeks of PT just to get it. This sydtem did to my PCP what was done to me. I was just supposed to meet that new clinician. I didn't think much of her. She may have read my chart, but no questions and she decided or was forced to tow the new policy. Pain clinic. So, I am out of a PCP. Instead of letting my PCP stsy put until she retired at the end of the year, they made her a float. So, I am out of part of my pain regimen. I am faced with a choice go to this person whonis on the board of directors on both hospital systems, not likely, or go eithout. Some days possible otger days not. So I am forced to improvise. The OTC isn't good for my kidneys and ine i have replaced with herbal the last, I still have plebty of. I am not an addictive personality. My PCP only prescribed a certain amount of pulls a month and she actually changed the script. I do better with those closer to the plant source, not the new stuff. If its not on the formulary, and my pain revs up, I am told to suck it up buttercup. This isn't good patient care.

Anybody who has been diagnosed with a mental gealth diagnosumis is automatically treated differently and finally vaccines. Kids are over vaccibated. I had to get a Td shot ss the company wanted anotger one. I am allergic to formaldehyde. My arm blew up like a balloon. When I asked gor manufacturer, lot number, expiratiin date and looked it up. It had formadeldehyde in it. That vaccine could have killed me! Nobody bothers to check meds anymore. People aren't protocols. Students csnnot get certain skills like physical assessments on AI generated programs. I ask questions to find out what is going on. These change based on my understanding of the person. I can ask a question 10 different ways. I don't understand your question because it hasn't been part of the program.

People deserve to get quality care. There are a lot of times I have to cancel an appointment, no transportation. Or if I need meds, and I don't have mpney for co-pays I can't get it. It's not about compliance although a person that I recently helped fell into that category, it's related to money or lack thereof.

Regards,

Laurie Cleveland

148 Trim Rd

Saint Regis Falls, NY 12980

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps everyone to live free, healthy and happy.

Regards,

Joan Conca

45 Grandview Ave

White Plains, NY 10605

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a 37 year old daughter who deserves to live her best life. She requires day hab services which enhances her social, mental and physical skills. She is an adult and deserves to live in her home with 24 hour supervision to be able to become as independent as possible. We as parents should not out live our children and therefore I feel very strongly that I set up a good support system for her now. These programs are so important to the special needs community. Please continue to support their services.

Regards,

Terry Brown

22 Ball St

Hoosick Falls, NY 12090

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it's our community! Who else will take care of it?!

Regards,

Jeremy Young

82-71 88th Pl

Queens, NY 11385

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am raising a special needs child.

Regards,

Christina Raptis

4 Deepdale Dr

Commack, NY 11725

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we must protect what's ours

Regards,

TYRONE LEE

6120 71st Ave Apt D3D

Ridgewood, NY 11385

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Medicaid remains important.

Regards,

Klaus Lessnau

300 E 93rd St # 36

New York, NY 10128

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because think of the children

Regards,

Joseph DeFeo

63 Crotty Ave

Yonkers, NY 10704

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because every member of the community is imprtant.

Regards,

Beverly Bullock

400 W 43rd St Apt 27B

New York, NY 10036

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because individuals with disabilities do so much to enrich their communities. They are dedicated employees, community members, friends, and family. They rely on community programs to live the types of lives that those without disabilities sometimes take for granted. It is our responsibility as members of our community to ensure that these individuals get the same opportunities to live meaningful lives as we do.

Regards,

Genevieve Thacher

1249 Front St

Binghamton, NY 13905

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I want to be part of the mainstream!

Regards,

Meredith Kent-Berman

235 E 22nd St Apt 12E

New York, NY 10010

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we care for our family and neighbors.

Regards,

veronica barajas

22 Garden Park Rd

Albion, NY 14411

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters because special needs people need assistance need supervision and they need to feel good about themselves. It really matters and changes lives for the better.

Regards,

Rita Aziz

1 Stony Run Rd

Great Neck, NY 11023

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities should have all the same opportunities as everyone else

Regards,

CAROL PRATT

354 Westmoreland Rd

Buffalo, NY 14226

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because. Thank you

Regards,

Polly Walker

3-37 Beach 40th St

Queens, NY 11691

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because as an Occupational Therapist I have treated children who needed the Medicaid Waiver to pay for equipment such as Wheelchairs, and Communication devices. I also feel that the community programs that support adults with different abilities are critical to their well being and keep them active in the community and out of residential care.

To remove these services would mean families would bear out of pocket cost for necessary medical equipment and differently abled adults would have fewer choices for community programming.

Regards,

Barbara Fitzsimmons

331 Seeley Rd

Corning, NY 14830

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am capable of living independently, but I need assistance with many of my daily living skills.

I do not drive so I need transportation to get groceries, meet up with friends and to get to volunteer opportunities. I love having my own place but I cannot afford my apartment and my utilities on my own. I want to be a productive member of society and with my DSP's help I can achieve my life goals

Regards,

Derek Curtis

4763 Norstar Blvd

Liverpool, NY 13088

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because without that we are taking away basic rights

Regards,

Krishna Dhru

9 Cold Spring Ct

Mount Kisco, NY 10549

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a son with disabilities. He receives services such as speech and psychotherapy weekly from AHRC in the Bronx. He has been attending this program since he was 18, he's now 47. He lives at home and has transportation provided by the program. AHRC has helped him communicate with others and learn to be a responsible adult.

Regards,

Len Carella

2418 Pearsall Ave

NY 10469

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I feel more connected to the place or people in the community.

We already warehouse people in Nursing homes and don't take them out to a restaurant or a movie or even a drive around to look at the Christmas lights. When you look at 4 walls day in day out, you feel like a number, a person just waiting to die.

People have to be connected to live and grow or simply to regenerate feelings of being connected.

Regards,

Elizabeth Barber

77 Arrowhead Ln

Penfield, NY 14526

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me ,-because my fiancé ,Erika ,-has worked in that field of caregiving for many many years... and I grew up with parents who volunteered each year for the Special Olympics and we also had a couple of my own family members,- who were

folks with disabilities... and the simple fact ,-that unalienable rights in our democratic experiment,- now under complete destructive attack by tyrant- traitor -toddler -Trump ...!!! and his criminal cabinet of project 2025 far -right- religious- FASCIST lunatics ...!!! has shown that they have no compassion or care for these matters whatsoever...!!!

Regards,

Daniel Mittermeyer

104 Greenleaf Meadows

Greece, NY 14612

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because People with disabilities and older adults deserve to live with independence, dignity, and connection to their communities

Regards,

Judith Jarer

18 Gillis Ave

Nyack, NY 10960

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Dear Congress Reps,

One of the things about living independently and having special needs is that i am alone. I do not have anyone assisting me. I could not pay for such important services without help whether it is the Arc or Bhsn. I have been diagnosed as having aspergers. I have physical disabilities. Medicaid and Medicare pick up the slack. I just want to ask that you please support those of us who are needy. Thanks for your time.

Sincerely,

Jb Pelkey

Regards,

Jb Pelkey

114 Oak St

Plattsburgh, NY 12901

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

I am the father of a 17 year old girl with autism and lgs ! My daughter has been badly treated by new york state , Franklin square schools , sewanhaka schools , Brookville school for autism ! Gov Hockul and gov Cuomo repeadly cut the budget for these children , to fund illegal aliens and other assorted criminals ! Long island school districts are top heavy with overpaid administrators who do nothing but warehouse these children ! Opwd the state agency in charge of these kids is still on covid lockdown, doesn't matter they do nothing anyway ! The agency's collecting money to help these kids are just money hungry thieves ! Nys needs to be investigated from the top down by Pam bondi and the fbi !

Regards,

James russell

145 Court House Rd

Franklin Square, NY 11010

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

My brother lives in a ARC home he couldn't live on his own he needs the assisted living the access to his medicines and ramps and tub shower wheelchairs can go in

Regards,

GREENE RITA

575 Evening Inn Rd

Oneonta, NY 13820

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we are united

Regards,

Annajean Morales

39-81 47th St

Queens, NY 11104

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a daughter with developmental delays and I am 68 yrs old!!!

Regards,

Mary Becker

325 Hudson Ave

Troy, NY 12182

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because without community, children can't learn, adults can't join causes, and all causes for justice would be lost.

Regards,

Jean-Paul Stiller

622 W 114th St

New York, NY 10025

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to my family. My nonverbal severely autistic son went psychotic attacking all of us this past winter. This was due to no programming available after aging out of school. He is now living in a residence 2 hours from us and has a dayhab program. It would be better if he was closer and he could have stayed with us. There aren't enough services for all that need them. My daughter is also autistic and in a dayhab program living home. These programs allow them to connect with other people in their community. We would be lost and struggling terribly without these programs and services.

Regards,

Darcy Janowski

1295 Simons Rd

Castleton-on-hudson, NY 12033

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I was just diagnosed with spinal stenosis, and have trouble walking and getting around. I may well be signing up for the home based community services soon and I will need them! Don't touch them!!!!!!!!!!!!!!!!!

Regards,

NANCY CROM

41 Russell Rd

Albany, NY 12205

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it benefits everyone.

Regards,

Ned Durkovic

PO Box 541152

Flushing, NY 11354

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we all need to help build up communities

Regards,

Linda Millemaci

171 Fowler Ave

Buffalo, NY 14217

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

My son now 43 is completely other abled in the early years, surgeries and treatments kept us busy

The school years came at a time when inclusion was the thing, he and we benefited from his education which was focused on what he could do.

Then as his age increased our ability to care for him diminished, and he agreed to go into a group home

Initially he was taken into the community on a much more regular basis where he enjoyed concerts and other things

Dayhabs do their best to followup but no longer provide those outside attractions

So at the end of the day he ends up in his room door closed (as his building mate is quite loud) recycling books tearing them appart page by page

So much effort was placed on preparing him for society only to have it abandoned after high school graduation He could hold a job but needs an attendant for toiliting

Regards,

Anthony Beck

2 Karen Dr

Silver Creek, NY 14136

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son is disabled and needs help in everything and everyday living

Regards,

Michael Bott

821-29 Country Pointe Cir

Queens, NY 11427

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

HCBS programs allow my daughter to get out of the house on a daily basis. She looks forward going to her Day Hab programs. Kerry's day programs provide activities that I could NOT possible provide for her. She also will never miss Friday's This is the day she gets to deliver meals via Meals on Wheels to the home bound. Kerry gets great satisfaction by helping others. If Kerry did not have these programs she would sit home on the couch and watch You Tube all day. This would not be good for her, her mother or me. She gets very frustrated when she is not able to go out into the community!!!

Regards,

Robert Wallen

224 Preston Ave

Staten Island, NY 10312

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm paralyzed and require 24 hour Personal Care to live at home.

Regards,

Keith Gurgui

9 Corwin Pl

Lake Katrine, NY 12449

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm 36 years old, I have a very active life with lots of friends and family who live nearby. I work, I do a lot of advocacy around disability related issues. I may able to do some gardening and have correct vegetables and have a wonderful dog I spend lots of time with. If I was forced into an institution my quality of life will go down the drain. I get much better quality of care with the help of my aides then the neglect I would have in a facility

Regards,

Zachary Hilty

18 Hanna Ln

Olivebridge, NY 12461

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it makes life easier and more familiar.

Regards,

Laurie Clothier

361 County Route 24

Corinth, NY 12822

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it is something I have never achieved as I continue -- alone --to have to subsidize and accommoate my ASD house mate for 25 years never imagining his brilliance and undiagnosed lifelong ASD would mean he has no conscience and his over ambitious, grandiose work projects produce NO financial results, under my roof as daily, my 79 yrs of life disbelief that I continue to pay a huge life price for this man. Yes, we oldies for whom there was no diagnosis or recognition daily pay a heave price. That said, continue your crucial work for everyone you are aware of, who needs it -- while I wish I had some help to support this severe dissociation and denial that daily takes a toll on my life.

Regards,

jude asphar

6 Hervey White Rd

Woodstock, NY 12498

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it is important to live up to their full potential .

Regards,

Sherry Yates

591 Conkey Ave

Rochester, NY 14621

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

My son Cole would be lost without his group home at New Hope Community

He is 28 and requires 24 hour supervision

He has Angelman Syndrome

Without government funding I don't know what would happen to him

My wife and I are seniors and there is no way we could take care of him

Medicaid HCBS is essential

Please continue to fund this program

Thank You

Regards,

Aaron Phinney

11 Harned Dr

Centerport, NY 11721

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because as a person with a disability, finding a group close to me who can support me is dire.

Regards,

Tyler Bridges

9 Hortons Mill Rd

White Plains, NY 10604

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we all need to feel connected to our community.

Regards,

Nancy Tomlinson

3051 NY-48

Oswego, NY 13126

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

I have two sons with developmental disabilities and their services improve their quality of life and integrate them in the community...

Regards,

Dawn Tortora-Morici

213 E Dover St

Valley Stream, NY 11580

Submitted on Sunday, November 30, 2025

Dear Members of the Special Committee on Aging,

In a world slashing Medicaid & many other life lines remember: behind these cuts are voices that are disregarded & ignored. Cutting Medicaid doesn't save money; it erases futures. My son

Jared, is a young man with Down Syndrome. At the present time Jared is enjoying the routine of his daily programs. He attends activities that are essential to his esteem and personal development.

Every morning Jared is up at 6:00am and preparing for his day. After leaving the house he arrives at his programs where he finds a sense of purpose, where he is part of the 'crew'.

He isn't in his bedroom fading into the background of life. Jared shows up. He has learned that he matters, makes a difference in the lives of others.

Should Medicaid funding be eliminated for Jared's programs, and services, he will sadly face many of the social & emotional side effects. Isolation, depression and hopelessness to name just a few. These are real issues that are as hard on the body as the most devastating physical illnesses.

Medicaid programs provide a purposeful life for Jared. He is happy, he loves the same things that you enjoy! He has great friends, he loves watching football with his father, he likes texting, laughing, joking and especially his daily 'work'!

Without the funding from Medicaid Jared will spend his days in his bedroom. Doing what? Well, I believe that question has clearly been answered here.

In closing I ask that you consider giving a voice to those who can't. Jared, as well as many others, deserve your undivided attention to this matter. They count on you to make the difference. They count on you to stand for them.

Respectively,

Angele LePage

Regards,

Angele LePage

6 Meadowview Ln

Massena, NY 13662

Submitted on Tuesday, December 2, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it gives those who are less fortunate than myself the opportunity to be supported in their learning of how to live on their own to their best abilities.

Regards,

Haley Walton

200 Stevers Mills Rd Lot 8

Broadalbin, NY 12025

Submitted on Thursday, December 4, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a Father of a 38 year old daughter with Down Syndrome. She is the oldest of my two children. She lives a very independent and meaningful life that I could never have imagined when she was born. Meghan makes the world a better place one day at a time and one person at a time. She does it by just being herself. Everybody that knows her will tell you how she has taught them so much. They have learned that the expectations are endless if these individuals are treated with respect and dignity. In my local community I am known as Meghan Buckley's Dad and very proud of that. My wife and I have been champions for the programs such as HCBS and many others because we know our daughter would not be where she is now without these services. I tell people Meghan is my "Peace Cloud" because she brings happiness and joy to everybody she meets or just people that happen to cross her path (i.e. airport, malls). She is living the best life I could have ever imagined. Then add onto someday my wife and I will not be around and her Sister lives on the other side of the country. We obviously will do all we can to leave her in a good situation but these support programs will always be required to maintain her quality of life. I would be honored to share our experiences to anybody that wants more details. I would fly to DC on my own dime to speak to anybody that wants to listen.

Sincerely,

Meghan Buckley's Dad Kevin

Regards,

Kevin Buckley

4327 Forestbrook Dr

Liverpool, NY 13090

Submitted on Saturday, December 6, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we are people too!

Regards,

Laura Kearins

1 Acorn Pl

NY 10465

NORTH CAROLINA

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to All, assisting those of us with lower incomes keep Dignity, Care, Compassion and Respect! Thank you All! Love Guides and Rules All!!! ♡♡♡

Regards,

liz saylor

Raleigh, NC 27601

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son is a recipient of CAP/C - a Medicaid HCBS program that supports children with disabilities. With this assistance, my son has a fantastic case manager who can connect us to resources, and my son has a direct support professional who he adores that can take him out in the community. CAP/C has provided us with an adaptable car seat for my son, who is 10 and still needs a 5-point harness, and an adaptable bike so he can ride a bike like his typical peers. Medicaid HCBS programs quietly provide a TREMENDOUS support to families like mine. Without this support, our son and our family would suffer. He would lack the necessary support we couldn't afford otherwise, and we may have to lessen our hours at work just to care for him. HCBS programs make for a better community - the whole family is supported, so we can support others, we can hold employment, and we can remain physically and emotionally healthy. I hope you continue to support these INVALUABLE programs,

Regards,

Ashleigh Swayze

223 Echo Lakes Dr

Hendersonville, NC 28739

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am 72 year 72-year-old male and I need to stay safely in my large rental complex of The Park at Midtown, off of W. Friendly Ave, Greensboro, NC 27410. It is very convenient for grocery shopping, my doctor's appointments, and other types of shopping at The Friendly Center in Greensboro, NC. So please ensure that I may live another 10 years of safe life in my Greensboro, NC, Apartment Complex.

Regards,

MICHAEL BURNHAM

5 Saint Croix Pl Apt 5M

Greensboro, NC 27410

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we need to value people at all ages.

Regards,

erika yucius

147 Legare St

NC 28411

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

I live in sec8 apartment complex I've Never lived in one before I have to say I Would never live in one again because Of the hate and noseyness over my Medical issues!

Regards,

John D.Dodd

149 Stonebridge Dr

Morganton, NC 28655

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

People with disabilities matter.

Regards,

Timothy Rushing

619 W Phifer St Apt F

Monroe, NC 28110

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

I have worked as an in home caregiver CNA for 21 years. Many of my clients are with Medicaid. Many have no other help and are barely making it. After April 2010 we were no longer allowed to go out once a week for Medicaid clients to get groceries or prescriptions. I was worried about them going without food or medicine and wrote many officials at the time, but to no avail. No one even acknowledged my letters. I did have clients who went without medicine and food at times because no one was available to pick it up for them and we were no longer allowed.

These people are desperate for care. Many are alone . If they have family, often they are just as old and sick as they are. Many try to put on an act that they are not as sick as they are because they fear being put into a nursing home and the era they were raised in was one where you were not supposed to admit your struggles.

The people I work with are struggling just to pay the bills each month and still be able to get groceries and medication. Some are just over the Medicaid limit and are struggling to pay their medical insurance (that must cover their many complex issues) on top of it all.

They wonder how they will get through the month. Then they have unexpected house repairs that must be done on top of it all.

The elder population deserves our respect, care and concern, not to be cast aside as if they will somehow be magically provided for by???

Who are we expecting? These people worked hard and paid into the system. One lady had a tragic work injury permanently disable her and take from her the profession she loved. The majority of these people are not lazy. Go through and find people who truly are abusing the system and hurting these who need it, but don't take it out on these people who worked hard and proud, depending on us to be there for them now.

Thank you

Sarah Hamaker,CNA

Regards,

Sarah Hamaker

Asheville, NC 28805

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a 71 year old woman who has been in a wheelchair since 1996. I became disabled because of steroids for my asthma which caused vascular necrosis in all my main joints and I couldn't walk anymore. I have been disabled and independent every since then except for last year when I had to leave the house my husband and I had bought because of domestic violence. I went into a group home then and it was terrible with people yelling at me and bossing me around. I have also gone into nursing homes a few times after surgery and hated the idea of living there too. I am a very independent person and I take care of myself. I have a lady come in 3 hours a hours a day to help me and I don't know what I would do without her help. I also don't know what I would do without my Medicaid help. I need my health care and benefits and my card

Plus I am under a Medicaid program that helps me in the afternoons. They pay 3/4 of my rent. They basically help me keep my mental health. If I loose all this I don't know what I will do, possibly suicide before I move in with my daughter in law.

Regards,

Deborah DeWeese

5085 Samet Dr

High Point, NC 27265

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I recently cared for my partner of 29 years at home as he had vascular dementia and was unable to stay home alone after a certain point in his illness. I was retired and worked only 2 mornings a week and had to have someone with him those mornings. His family was not present for his care unfortunately. Careyaya.org stepped in and helped me with a referral from Duke Family Care Services. Without community care, I dont know what I would have done without referrals from care groups and my Careyaya. We have very little money and are both on Medicare. The nurses who came were from Medicare were lifesavers I will say. They prepared me for everything that happens with dementia/alzhiemer's patients and for the end of life progression. I had to leave my job when his disease progressed as I could not afford full-time care for him. His life ended peacefully but it was very hard on me. The Hospice people allowed me to bring him to a facility for 5 days to give me a rest which I very much needed. He died not long after his Hospice stay in August of 2024. Shortly thereafter at Thanksgiving, I had a stroke and was unable to care for myself. Luckily, I have a son nearby and stayed with him until I felt stronger. Without community support, we would not have been able to be at home with our loved one. Thank you for helping us.

Regards,

Paula Poe

806 Davis Rd

Hillsborough, NC 27278

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because without it my son couldn't have direct care workers to provide my mother, who has been my caregiver for 25 years a break and down time. My son is wheelchair bound, has Epilepsy, blind and 100% care for all ADLs. People like my son need these programs to thrive and survive.

Regards,

Crystal Boyce

827 Stone Cross Dr

Spring Lake, NC 28390

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my youngest son is severely & profoundly Autistic & non verbal. If he were not getting professional community inclusion services, he would never leave his AFL home & would not get to experience the world in a way that is "normal" for everyone else. My son deserves to go shopping, dine out, see a movie, go to the park, hike trails, catch a fish, see waterfalls & all of the wonders of nature he cannot view from his window. Without these services, my son may as well be a prisoner in his home which is completely unfair to a young man who has never done anything wrong in his life. He has already exceeded the lifespan for persons with his particular disabilities. We do not know how much time he has left... please allow him the freedom to enjoy that time. Thank you.

Regards,

Marjory Moore

Shelby, NC 28152

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we have to live and respect each neighbor as you would expect to be.

Regards,

Randy Jones

1422 Vandenberg Dr

Fayetteville, NC 28312

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it's important!

Regards,

Eileen Juric

511 Adams St

Raleigh, NC 27605

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son deserves to feel like a productive member of society. He works for the ITS dept at UNC 12 hours a week, 11 mo a year, since he graduated HS in 2017 (not counting 2 yr layoff for pandemic). He enters data into software that is being tested. It's a repetitive, tedious job and he excels at it. So he is a valued employee. But UNC will not hire him without a job coach 4 hours a month. Having autism his social, analytical, and communication skills can cause misunderstandings between him and his superiors. This occurs when it comes to annual re-employment, training on new software, etc. Medicaid pays for this up to 4 hours a month of job coach time. It allows him to get up and get on the public bus every morning (with other neighborhood commuters) to go to an office desk where he is part of a team and appreciated for his unique skills. He collects a small paycheck which supplements his SSDI. This is the only service he gets.

Regards,

Marie Corwin

1 Banbury Ln

Chapel Hill, NC 27517

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because https://youtu.be/jeOf2n9ZO2M. Here is our story from a few years ago on the today's show.

Regards,

Ruth SingerStrunck

4801 Aspengold Ct

Monroe, NC 28110

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my adult son depends on these services in order to live in the community. My son is non verbal, has severe autism, significant intellectual disability, epilepsy, and chronic gastrointestinal issues. My husband and I are senior citizens, and we would not be able to care for our son with out help because he requires 24/7 care. I fear for my son's future, especially as our services are in danger of being cut. Please don't cut the services that our loved ones need!

Regards,

Donna Austin

5403 Greywood Dr

Greensboro, NC 27406

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Hundreds of thousands of Americans with significant intellectual and developmental disabilities are on waitlists for services, often more than a decade long. They either lack support services entirely or only have them partially, inadequately, and ineffectively.

These precious intellectually disabled Americans are part of every demographic population, including every racial and ethnic group. They are white, Black, Latino/Hispanic, Asian, Indigenous, Middle Eastern, biracial, and multiracial—every such identity designation. They live in every geographic region, every state, and every local community. They are born in families of every socioeconomic class and every partisan political group, including Republicans, Democrats, and independents.

There is no group of Americans more vulnerable and at risk than those with significant intellectual and developmental disabilities.

When we fail these intellectually disabled Americans, they do not receive proper care. They frequently fall into crisis. They become ill. They become homeless—they make up a disproportionate part of our homeless population. They are victims of sexual violence and sexual abuse at truly unfathomable rates. They become substance dependent. They die prematurely, and perhaps even worse live awful lives of desperation, marginalization, and genuine suffering—not because of their disability but because of our deficits of care, connection, and inclusion.

These are real Americans living far too poorly and dying far too early.

But we almost never talk about them. Americans with significant intellectual and developmental disabilities are not important enough for us to talk about them.

The waitlists also mean that many Americans with intellectual and developmental disabilities lack needed support throughout their entire childhoods, when certain therapeutic services might be most effective and impactful and have the potential to change the course of their lives for the better.

My child's life tells the story of what can happen when supports and services are made available. It's not a perfect story, of course, but it's a good story.

Nicholas has had a Medicaid waiver specific to North Carolina—initially called a CAP waiver and now called an Innovations Waiver—since January 2010, when he was 9 years old. Nicholas is autistic and intellectually disabled, with co-diagnoses of severe mixed expressive-receptive communication disorder, obsessive-compulsive disorder, sensory integration disorder, socialization delay and impairment, and tic disorder. When he received the Medicaid waiver, he was prone to tantrums and self-harm. He also has a physical disability with severe ulcerative pancolitis. When that onset in 2016, Nicholas lost

25-30 pounds and was hospitalized for a month—he now receives medication infusions for several hours at an infusion center every eight weeks.

Now 25, Nicholas has a good life. He volunteers every week both at MANNA FoodBank and at Asheville Buncombe Community Christian Ministry. He works a few hours each week at a paid job at an ice cream shop, Annie B's Homemade Ice Cream, that has extra support for its workers with disabilities. He has social connections through community groups and therapeutic recreation programs. He swims and shoots hoops at the Y. He goes to camp some summers. He likes to go on walks and hikes, and he's an impressive juggler. He has a girlfriend, who also is autistic and intellectually disabled.

Nicholas can never live independently without support. But he is not in an institution, and he is a vibrant, valued, and contributing member of his community. So much of his life is possible because of the services he receives, in combination with a community support circle and, well, me. He has a support worker for several hours each weekday right now—even with the Direct Care Worker workforce crisis—and that helps anchor his well-being and community participation.

Without the Innovations Waiver he received at 9 years old, I truly believe—I know—most of this would not have been possible. I want the possibility of such lives for all our children and adults with significant intellectual and developmental disabilities.

Surely, we all support far better circumstances for Americans with intellectual and developmental disabilities. We want to support families and one another and help take care of our children and adults with significant IDD.

That's the stand we have to make, every day, every one of us: No more generations of hundreds of thousands of Americans with IDD living and dying in desperation.

Urgently, we must end all the waitlists for services and community inclusion for Americans with significant intellectual and developmental disabilities—to improve the lives, well-being, and health of every at-risk and marginalized intellectually and developmentally disabled person, because they are an essential part of us.

Surely, at last, we know: They *are* us.

Regards,

Ray Hemachandra

911 Cranbrook Dr

Arden, NC 28704

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it represents connection, strength, and resilience during times of struggle and uncertainty.

Mother and I receive Medicaid and we definitely need basically for survival. Without it, we might not make it.

Regards,

David Hollingsworth

1508 Diamond Rd

Fayetteville, NC 28311

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters for All, keeping people Home, Healthy and Respected, Thank you All! Love and Care!! ♥♥♥

Regards,

liz saylor

Raleigh, NC 27601

OHIO

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because. For more than 10 years I cared for a quadrapalegic. I know and understand their emotional and physical needs. They deserve the same respect as any person who can walk or go about their daily lives.

Regards,

Gerald Young

8125 Seward Ave Apt 392

Cincinnati, OH 45231

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a totally blind 40 year-old woman with additional disabilities, including autism level, one with no intellectual disability, ADHD, complex posttraumatic stress with dissociation, EHLERSDANLOS disease, non—24 hour sleep WAKE disorder, fibromyalgia, chronic fatigue, long-term damaging effects of bacterial pneumonia, Covid, psychotropic, medication, overuse, chemical/pesticide, exposure, hypoxia, acquired hearing damage, processing trouble, debilitating migraines with several hits to my head, seizures, etc. I am someone you would think would need come home and community based services however I was in fact a care provider. I was on both sides. It's assumed that I would have staff in my home. I know many others who need someone to take them to the store, help them pick out groceries, do their laundry, clean their homes, accompany them to medical appointments, bathe dress, and feed them, accompany them to work, lift them if they fall, etc. This in fact does not apply to me however, many other others do you need the services. I live with a dual Medicare Medicaid plan, supplemental security, income, benefits, and a rent subsidy that do not allow me to marry, have a child, adopt, foster, earned enough to file an IRS 1099 form, open the animal rescue/long-term care facility I'd always hope to. I had cared for my dearest friend who had traumatic brain injury. She passed away over four years ago because of perception of both of us. Her family assumed that I would need HC services when I was trying to become certified to care for

her. I have apps that provide visual and auditory interpretation on my phone, devices that can read cash, etc., screen readers that speak text on computers and mobile device devices, GPS applications, which help us find directions to destinations, text to speech, color, identification, etc. I perform most tasks by feel. We also have durable medical equipment that talks to monitor bodily signs and refreshable braille displays with electronic pins that move we can write, edit, word process, as well as pair Bluetooth to smart phones, computers, and other mobile devices. This is why I do not require home and community base services. I aspire to become a certified 24 hour in-home caregiver however have received backlash because I am multiply disabled. I cannot prove the experience I've had doing this since before I was 16 years old. HC services are very important however funding to pay for the previous mentioned devices as well as the application purchases and subscriptions that we use which use our phones camera or a human volunteer or trained agent to look through a camera to provide any aspect of visual interpretation, such as reading restaurant, menus, print documents, medication, information, cooking instructions, recipes, mail, personal medical and financial paperwork, photo IDs, insurance cards, etc., then typing up this information. Emailing it to us, checking TV guides for us, helping a shop online, etc.. We also need the coverage for these services that could be considered blindness specific. Doctors do not know what these applications and technologies are therefore they're not signing off on them. Medicaid has got to cover these applications and devices as well as the durable medical equipment that is accessible to us so we're not having people do for us. We fight too hard to pay for these technologies. I as a an aspiring home and community based services provider yes living with several disabilities and occurring health conditions and full support of the advancement of HC services. There is a shortage and if people were not assumed in capable just because of condition and external appearance without anyone dropping the assumption that we Cannot when they don't know what these disabilities actually are, many of us could actually become care providers.

Regards,

melody Holloway

1270 Brown Rd

Columbus, OH 43223

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because disability services Provides Direct care workers

Regards,

Caiman Hobeika

4124 Sargasso Ct

Cincinnati, OH 45251

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to my son, because it allows him to have friends, go places and decide what he wants to do, like going out to restaurants, movies and other fun places. He can live in his own house, decide what he wants to eat and what he wears. If he were in a nursing home most of the things I mentioned would not be available.

Regards,

Melanie Marquis

16412 Hengstler Rd

Wapakoneta, OH 45895

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

IT'S. OUR RIGHTS TO AND OUR CONSTUTIONAL RIGHTS SO STOP TRYING TO TAKE IT AWAY FROM US .....AMEN

Regards,

Daniel Scullion

975 Madison Ave

Alliance, OH 44601

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a completely blind homeowner who works 8 to 12 hours a week and needs to be able to get out of his house in order to interact and have fun in the community and without medicade resources such as this and other programs I would be stuck inside my house, isolated and unable to get out to access the resources that I need to access in order to live a good quality of life unlike my sided peers who are able to get out without any problems

Regards,

Brennen Kinch

3645 Kohn Dr

Fairfield, OH 45014

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me.

Regards,

Karen Smith

1722 E 337th St

Eastlake, OH 44095

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Programs like Medicaid Home and Community-Based Services (HCBS) have a profound impact on our family's life. These supports are essential for my son, who has non verbal autism, and my brother, who has Down syndrome. HCBS is not just a program for them — it is what allows them to live with independence, dignity, and real connection to their community.

Because of HCBS, my son and brother are able to stay in their home, participate in daily life, learn, grow, and be surrounded by the people who love and understand them. These

services help them attend school, work toward their goals, build relationships, and be active members of the community — not isolated or placed in an institution.

Life in the community matters to us because it gives my son and brother the chance to be themselves, to be included, and to be valued. Being part of everyday life allows them to develop skills, make friends, feel safe, and experience joy and belonging. It lets them contribute to our community in their own meaningful ways.

Without Medicaid HCBS, our world would look drastically different. My son and brother would lose the supports that keep them safe, engaged, and able to thrive at home. They would lose the opportunity to live the full, connected lives they deserve. These services are not optional — they are lifelines.

People with disabilities deserve the same opportunity for independence, dignity, and community as anyone else. Our family's experience shows why HCBS is essential and why life in the community must be protected.

I hope our story helps Congress understand what is truly at stake and why programs like Medicaid HCBS make a real and life-changing difference for families like ours.

Regards,

charles Tribett

411 W State Line Rd

Toledo, OH 43612

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because this allows my son Tristan, who is 25 and has severe autism, to attend a day program and participate in weekend sleep away camps.

Medicaid funds not only pay for these essential activities which improve his quality of life but also pays for the transportation to these programs.

Medicaid also pays for independent providers who can care for him at home so he does not end up in a group home or a residential facility.

Regards,

Vicki Larson

5580 Barton Rd Unit 302

North Olmsted, OH 44070

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son deserves to be a part of our larger community with his brothers.

Regards,

Emily Billings

187 S Southampton Ave

Columbus, OH 43204

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a person with a disability living in the community. I enjoy to go out in the community every day and ride the public transportation and engage with others in the community people often with disabilities also. I also enjoy to engage in talks with the veterans in the community many often say that I am a good listener and a good person to talk to. That is just some of many reasons why community living matters to me

Regards,

Ashley Thompson

Groesbeck, OH 45239

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities deserve to live with as much independence and dignity as possible.

My family branch has 3 individuals with various handicaps. When I was younger I worked in a care facility for adults 18 & over with various mental and physical handicaps that made it impossible for home care at that time. With HCBS Medicaid they can now remain at home as part of the family and be a part of community activities. These are the nicest, sweetest people you would ever want to know. The fact their families can rest easy that their loved ones can be cared for at home means everything to them. Please do not disrupt funding for such a worthy effort.

Regards,

Beverly O'Hara

12023 Ashbury Ave

Cleveland, OH 44106

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my grown son Dan has autism. Dan has used/is using HCBS for supported employment, non-medical transportation, and case management. Dan worked in an enclave that was specifically for individuals with Developmental Disabilities, in the community. Dan needs non-medical transportation to go to the grocery store, arts group meetings, to go to the doctor/dentist, see his counselor, etc. Dan has case management, an SSA, through the Board of DD. He has a Level 1 Waiver. He attends ADS M-Th. Dan lives in an ARC house. Unfortunately, I do not own a car, and cannot give Dan rides. Dan needs his non-medical transportation in the community to get what he needs like food, clothing, OTC. Dan's SSA writes his ISP, which makes sure that all Dan's services and supports are on the same page. Dan also uses a Payee at the Board of DD, especially since his dad is in the nursing home with no discharge date. I am disabled. That makes the services and supports that Dan gets with HCBS all the more critical. Thank-you. God Bless!

Regards,

Rosemary Kohnen

Carthagena, OH 45822

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

I live in a retirement community. WE have a complete array of service/needs. It ranges from independent, assisted living, medical care needed, Early dementia (can do personal care) and serious dementia (need complete care). I am independent, but friends need medical assistance and my husband was completely dependent dementia. Without the financial assistance of Medicare we would have lost everything - not just our house. Too many seniors need assistance - only heartless idiots would cut the lifeline that Medicare/medicaid provide.

Regards,

Roberta Farinet

3218 Indian Ripple Rd

Dayton, OH 45440

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it is at this level that my direct interaction takes place.

Regards,

Jason McMahon

11550 Olde Gate Dr

Springdale, OH 45246

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because the conditions of assisted living facilities are dreadful. I visited a site that had a floor in the building known as the death floor. I've been disabled since 2009 and continued to work until 9/2019 when my health started to significantly decline. Moving into senior housing will provide people to check in on me on a regular basis and allow me to have quality of life that I wouldn't receive in assisted living. I can afford to live in senior housing ... not in assisted living that takes every dime you have

and allots only $50.00 for toiletries, laundry supplies, and small food purchases. It is far more cost effective to help people in their homes than in a facility.

Thanks so much for reading my message and have a lovely day.

Regards,

Colleen Lee

7425 Country Village Dr

Cleves, OH 45002

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because these individuals needs a good home to live and enjoy life in a peaceful environment . I see the joy in their faces when they say they are going home to their own places of their own place . They feel independent and happy to tackle problems if any on their own .

Regards,

KOFI AKWETE

9578 Nathanial Ln

Fairfield, OH 45014

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my family's health and financial security depends on it.

Regards,

mark mendoza

4372 Virginia Ave

Cincinnati, OH 45223

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

people with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. HCBS help make this possible by helping people stay in their homes, attend school, work, take needed medications, get to see their much needed doctors, get the services they need and participate fully in their communities.

Regards,

Randi Renninger

1722 W North Bend Rd

Cincinnati, OH 45224

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Medicaid HSBC Community living matters to me because my son with Down Syndrome, Sensory Processing Disorder, Autism, Type 1 Diabetic, (Severe pancreatic difficuency) and fed through feeding tube. Disability Providers, Case Workers and Community Based Services are so very important for my Son and 100's of thousands of other people with Disabilities. They are citizens of our United States, born here and have meaningful lives that truly matter in our Country. Home based help matters greatly as this helps them a lot and their Caregivers to help those with needs succeed. Help at home, schools, Community work, help them to be more independent and thriving people. This is very important to all of these families. Critical. Thank you for hearing our own life story. Please, Please, Please continue the help for those that especially need it. They deserve this and this should never be an option! Ever!

Regards,

Tonya Fisher

Kettering, OH 45439

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it will continue to make a huge impact to a good percentage of our population! I have worked over 20 years with aging individuals and individuals with disabilities. I have seen how programs such as job coaches, employment services, personal assistance, transportation, respite care has changed lives! Not only the lives of individuals with disabilities, but those who care for them, family and friends, a ripple effect that affects the entire community! These are essential programs to be supported. Without these programs, we can face a real risk of unnecessary institutionalization which will diminish their quality of life, and also increase costs.

It all around, supports a healthy community being able to live on their own in the community, to work and maintain a job to enjoy hobbies And be close to family and friends for support.

Prioritizing the services ensures that people with disabilities have choices in all aspects of life and can thrive an integrated settings!

Thank you! I believe this is important! I'm grateful for the opportunity to write this letter and to share my thoughts and passion and heart for the lives of many people I love!

Sincerely!

Regards,

Jill Chapin

Cincinnati, OH 45251

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows my special needs daughter the opportunity to be included in her community activities, work force activities and community inclusion as a whole. Through the supports provided under Medicaid HCBS benefits she has had the opportunity to personally engage with many people through out various communities that know her when they see her and she has developed a personal rapport with many of them. She has developed employment skills through the SAW program funded by Medicaid HCBS. She feels apart of she community and it provides her with a sense of inclusion. Although, she has special needs, she is still connected and

accepted as a citizen just like everybody else. She had developed her own sense of independence and knows that she has rights just like everybody else does. Without the supports of Medicaid HCBS this would not be possible for her.

Regards,

Diane Jonel

17500 Libby Rd

Maple Heights, OH 44137

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it does

Regards,

Bianca tropeano

2693 W State Route 29

Urbana, OH 43078

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to Me because I want every artificial intelligence data center to be shut down indefinitely because for artificial intelligence data centers to remain operation is the root cause of inflation!

Regards,

Timothy Carrington

5216 Quincy Dr

Columbus, OH 43232

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters immensely to my son, Jason Hummel, because he needs to feel included and noticed by others for his accomplishments and for just being who he is. He attends a workshop were he feels he has contributed to society and it gives him a purpose and routine on Monday-Friday. Medicaid HCBS helps him by keeping doctor appointments, shopping for meal preparation, with transportation and his informed consent. Please do not reduce services for HCBS. People with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. HCBS help make this possible by helping people stay in their homes, work, and participate fully in their communities. Independence matters to him!

Regards,

Tere Hummel

3696 Elmhurst Ct

Kent, OH 44240

Submitted on Friday, December 5, 2025

Dear Members of the Special Committee on Aging,

Community living matters to our family because without it, we would either go back to living in extreme poverty or my adult daughter with disabilities would have to live in a group home without access to a sign language interpreter leaving her unable to communicate with those who would be caring for her. My daughter's HCBS allows her to live at home with me (her mother) and her siblings. My daughter has severe developmental disabilities and is Deaf. In order to communicate she relies on American Sign Language. Meaning, those caring for her need to be fluent in ASL or she requires an ASL interpreter. HCBS allowed me to become a certified provider through the Ohio Department of Developmental Disabilities so that I could provide services in the home for her activities of daily living. I am also the only certified provider in our county that is also certified in American Sign Language. HCBS also allows for my daughter to access an adult day program, community inclusion activities and more because HCBS provides access to an interpreter for her. If cuts are made to HCBS, my daughter would lose access to those services. She would lose access to her program because there would be no access to an interpreter and additionally, being her provider allows me to generate an income for the care I provide for her. Because she is 24 hour care, I am unable to work outside the home fulltime to sustain meaningful income. If HBCS were cut, my ability to generate an income would live us in the position of like I

previously mentioned, going back into extreme poverty, or my daughter having to be placed in a group home so that I could work outside of the home. But keep in mind the cuts in HBCS would mean no access to an interpreter in a group home. Cuts to HBCS would mean either extreme poverty, or a life without dignified care or being able to communicate with anyone, leaving no access to the community at all for my daughter. HBCS allows my daughter to be with her family and friends, allows her to access her community, it allows her to live a life where her civil rights are fully intact. Home and Community Based Services are our families lifeline to being a part of our community. It would be devastating to lose access to these services for our entire family.

Regards,

Amanda Fontana

810 Quaker Ct SW

New Philadelphia, OH 44663

Submitted on Friday, December 5, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter matters. She attends a Day Program at a community animal welfare league. She is able to learn daily living skills, have friends, be part of the community and help care for the animals until they are adopted. She is a valuable member of the community. I want everyone to see her and not the dollar sign behind her care. She is healthy and thriving because she has support. A parent can only do so much and we will not live forever. We need her support and services to continue.

Regards,

Rochell Stufflebeam

607 Basswood Dr

Springfield, OH 45504

Submitted on Saturday, December 6, 2025

Dear Members of the Special Committee on Aging,

Community living matters to my son, who is 29 years old nonverbal with severe autism, I am my son's paid caretaker by the state my son is on the Ohio shared living waiver, I have been taking care of my son at diagnosis at 2 years old since Dad and I divorced, Daddy went on with his life autism free as he is now still, I gave up my entire life to take care of my son at diagnosis and we only lived on his social security and his child support from his father dad has not helped out since our divorce with my son, I wasn't able to work all those years because I had to care for my son I had to quit my job, he finally got approved for the Ohio share living waiver 5 years ago if my son would lose this waiver my son and I would be homeless in the streets, we have no family to take us in my parents are dead, my son's father currently wants nothing to do with his son he doesn't care about his son he doesn't help me get any breaks from his son breaks from caregiving,he lies to my son and says he'll come see him my son waits for him he's a no-show his birthday was September 13th dad lied to him and said he'll meet him at the mall he was a no-show my son cried that day ,he did nothing for my son's birthday is doing nothing for him for Christmas we cut that out of our life due to the way he treats my son, my son is my best friend my son is my best buddy I love him and I will take care of my son till I'm old and gray I don't want my son to lose his waiver and him being homeless, having his waiver means everything to him he lives with his family, he goes out in the community and does activities that he enjoys like going to the mall, bowling going to the library, going to the laundromat, going grocery shopping he enjoys being in the community and doing activities with Mom.Im his whole world he knows I take care of him and love him and he knows his dad is not here and doesn't care for him. At 50 years old I'm still dedicated to taking care of my son that he is first before myself as he always been, he didn't ask to have autism he did not ask for autism to Rob his voice and Rob his entire life, my son needs 24-hour care 24-hour supervision he cannot be left alone he's been nonverbal since 2, please continue to fight for our disabled population fight for our waivers fight for our children and adults with disabilities to stay in their communities please thank you

Regards,

Amy smith

3491 Almerinda Dr

Canfield, OH 44406

OKLAHOMA

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because if we keep stepping on our selves then when we see that we are few in number, and then we won't have any one to speak for the rest of us, and we will be done on this Earth

Regards,

Paul Scott

4641 Woodland Blvd

Oklahoma City, OK 73105

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I want a safe place to live.

Regards,

Christine grabar

6532 E 21st Pl Apt 314

Tulsa, OK 74129

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it's the right thing to do.

Regards,

Dale Bushyhead

1203 E 143rd St

Glenpool, OK 74033

Submitted on Tuesday, November 25, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my husband passed away and I could no longer stay in my house. Medicaid has helped me be able to live in senior housing because I have a provider comes 3 days a week. She does my shopping and pays my bills. Then she does my laundry foldsand hangs up. She does my dishes each time. Then she cleans my apartment bathroom, bedroom, living room. She sweeps, mops and dusts. Without the service I have Noone to help me. I would end up in the nursing home which is under staffed. I still have my independence. Please don't cut. There are a lot more people out here that need this help then are cheating at it. Don't punish those of us that need this help.

Regards,

Cletara Mitchell

1036 Ridgeview Dr Apt 6B

Madill, OK 73446

Submitted on Monday, December 8, 2025

Dear Members of the Special Committee on Aging,

Our identical twin daughters are 24 years old and receive waiver services due to the challenges they face from having Phelan McDermid Syndrome. This funding allows them to be part of the community, with direct care personnel supporting each of our daughters. They need this support to ensure safety, self-care, and social interaction. This program allows my husband and me to maintain full-time jobs as professionals. These services are vital to the mental and physical health of our entire family. It provides respite care, so my husband and I can take breaks. It widens the circle of caregivers who know our girls when we might not be available in an emergency. It improves the girls' mental health by providing opportunities to get out into the community and attend a day center. Check out SunhiveCollective.com to see some of the great things these funds support.

Please continue to fund these programs and consider giving additional funding to reduce the wait list for those who desperately need these services.

Regards,

Traci Sutton

204 SW 166th St

Oklahoma City, OK 73170

OREGON

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because not only am I physically disabled, I also have seizures. Living at home with my parents, who take care of me, but also schedule my medical appointments for me is a necessity. My mom is my personal support worker and she does a great job of making sure I am safe and cared for. Medicaid pays for my medications and the HCBS pays my mom for the care she gives me. I get out in the community weekly with a paid support person as well. Their funding is so important! I spend my money in my community and am a productive citizen. Please keep funding Medicaid and HCBS. My life depends on it! Thank you.

Regards,

Anna Cole

1109 NE Locksley Dr

Bend, OR 97701

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it keeps people closer to their families, and loved ones, supports in their communities, where without suck programs, and support workers, these people would either end up in facilities, with no autonomy and quality of life, losing meaningful connections and purposeful activities that help them thrive. Many would end, sadly, houseless or on the streets in shelters without proper care or support.

Regards,

Juanita Rinas

975 Lewis Ave

Eugene, OR 97402

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am disabled myself and if it wasn't for partial Medicade I wouldn't be able to have a power chair to get to my appointments and take my emotional support dog out and to beable to go to fun things. It would be hard for my wife to have to wheel me everywhere.

Regards,

Ty Young

1040 NW 10th Ave Apt 542

Portland, OR 97209

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, I serve adults with developmental disabilities as a case worker. Most of them work, but cannot work full time, due to their advisability or that the type of jobs they have do not offer full time. They want to live on their own and can with some supports, but housing continues to be a challenge as they are priced out. If they did not have medicaid they would not have health insurance, service providers to support them with living as independently as possible, and most likely end up on the street or die. They also could not move into a group home or foster care, as this is supported with their income and medicaid. If medicaid stopped then providers/family member will need to work elsewhere and the person will be lift alone and have no supports, some of them could die or get increased health problems, adding to the strain of the ER department.

Regards,

Cindi Otis

11270 NW Kenzer Ct

Portland, OR 97229

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter has had an intellectual disability since birth and is now 40 years old. Her significant disability prevents her from using transportation on her own, and due to her disability requires 1:1 support to all her appointments, assistance with scheduling and managing appointments and assistance with medication and she cannot cannot get to doctors appointments without having a PSW (personal support worker) to assist. Also, without funding for Medicaid hours for groups she has no friends or group of her peers to associate with which would leave her stand alone. People with disabilities deserve to have these services in order to have any quality of life. Without them it would be just as bad as the old days when they locked them in institutions. Please understand how heartless and cruel this would be. Thank you.

Regards,

Rosemary Schifferling

2807 Strasburg Dr

Forest Grove, OR 97116

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I live in rural Oregon. I was born and raised in the city. Aging popilations here seem to quietly get old and frail, silently dieing in their homes not knowing the support avenues available to them due to lack of social interaction. Meals on Wheels and adult rehab is very much needed here. The cost of Medicare and Medigap plans are too expensive and poor coverage. We need Medicare for All.

Regards,

Joel Nista

1171 W 11th St

Coquille, OR 97423

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because working in education and vocational training with adults with disabilities taught me that independence is a learned behavior. That improves quality of life and cost of supports to taxpayers.

Regards,

Steve Campbell

4927 Oceana Dr

Florence, OR 97439

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am the Power of Attorney, Authorized Representative, and Representative Payee for a woman on disability who had 4 strokes and survived, and who still has cognitive limitations, aphasia, a contractured hand and arm, and difficulty walking. Prior to her strokes, she was a caregiver who was excellent at her work, and was able to work with difficult clients to help them accept care. She was able to go to an assisted living in 2021 and stay for 4 years during which she actually got rehabilitation which was not set up during the first 3 years after her strokes. She made great strides as the result of physical and occupational therapy, specialized medical care in many areas, and overall support to help her heal. She recently got into her own apartment and now has in-home care while living in the community. She would not have recovered to this point without long term care services to assist her in getting her basic care needs met because she has aphasia (cannot find words to express herself and has memory problems as well) and cannot articulate her needs or coordinate needed services. She still needs a home care worker to manage her cognitive deficits, as she does not notice what she has missed a lot of the time, she often cannot find words to request what she needs, and she has trouble reading and writing consistently and sufficiently to solve day to day problems. I only recently became her community advocate in 2022, and until 3 years ago, she has no one consistently who advocated for her. She gained these services when she went into assisted living, and she is now in need of a little less support as a result. This has helped her dignity tremendously. It also saves the system money to have her in an apartment

getting less intense care. If she has not had Medicaid HCBS she would not been able to track her care needs, would not have been able to make appointments or get to them, would not have been able to explain what she needed to medical providers, and would not have gotten the care she received in order to improve her overall health. She would still be unable to read at all, she would not have corrective lenses in order to see, she would not have dentures, and she would still be depressed and unable to function. These services literally helped her turn the corner toward recovery and being able to do many more things independently. She still needs support to remain independent, and benefits markedly from these services so she can live in a way which allows her to have dignity and choice. She has been sad and devastated for years because of the inversion of roles from caregiver to the one receiving care; she benefited from the help she received most recently and made progress because of it. She is delighted to be living on her own and is rarely depressed now. She has the support she needs to manage her life and the independence she wants in order to have self-respect and dignity. These services are vital for many. Please support them remaining funded and available to vulnerable people who would eventually either end up in more costly settings or who would become homeless and not survive for very long. Thank you for reading.

Regards,

Paula Jackman

8875 SW Bomar Ct

Portland, OR 97223

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living! Doesn't that imply everything anyone needs to know? We're all in this together and we need to support each other through these horrifically trying times.

Regards,

John Anderson

4297 Apple Ct NE

Keizer, OR 97303

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am unable to walk in a grocety store. My arm has been broken for more than two years and I cannot take a bath by myself.

Regards,

Debra Snipes

1687 NW Division St Apt 319

Corvallis, OR 97330

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because you have SO DECIMATED WORKPLACE RIGHTS and people LOSE THE USE OF THEIR EDUCATION AND EXPERIENCE TO COVER UP FOR CRIME AND ABUSE

Regards,

Nina French

8647 NE Tillamook St

Portland, OR 97220

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I want to able to live on my own some day.

Regards,

Jennifer DiBello

18525 SW Rigert Rd

Beaverton, OR 97007

Submitted on Thursday, December 4, 2025

Dear Members of the Special Committee on Aging,

To the Members of the Senate Special Committee on Aging,

My name is Nathan Buckalew, and I am the Co-Founder of Empowered Care, a small, family-operated disability support agency in Oregon. Long before I became a provider, I was simply a brother. I grew up supporting my sister, who has intellectual and developmental disabilities, and because of her, I saw up close how essential compassionate, stable, and person-centered support truly is. My sister shaped my entire understanding of what dignity, independence, and meaningful community inclusion should look like for every person with a disability.

Medicaid Home and Community-Based Services (HCBS) changed my family's life, and it is the reason I chose this career. HCBS allowed my sister to remain in our home, stay connected to her routines, attend school, and grow in ways that simply would not have been possible in a more restrictive setting. These services supported not only her—but all of us. HCBS gave my family the peace of mind that she was safe, supported, and able to live in the community she loved.

Because of what HCBS made possible for my sister, I built Empowered Care with the same values I learned as a sibling: respect, consistency, compassion, and true community inclusion. Today, we support individuals and families across multiple Oregon counties, many of whom rely entirely on Medicaid-funded services to remain in their homes and maintain their independence. We see firsthand how HCBS prevents unnecessary institutionalization, keeps families together, and creates opportunities for people to live full, connected lives.

If HCBS did not exist—or if funding or workforce shortages make services inaccessible—people with disabilities would face devastating consequences.

Without HCBS:

Many individuals would lose the ability to remain safely in their homes.

Families would be forced into impossible caregiving roles without support.

Parents would leave the workforce to care for their children.

Adults with disabilities would lose access to their communities, jobs, and education.

Provider agencies like mine would not be able to maintain a stable workforce or meet the growing need for services.

In short, HCBS is the difference between community and isolation, between independence and institutionalization. I have seen the impact as a family member, an advocate, and now as a service provider responsible for both the well-being of individuals and the workforce that supports them.

As someone whose entire purpose in this field started with caring for my sister, I cannot overstate the importance of HCBS for millions of families like mine. These services do not simply “help” people with disabilities—they uphold their rights, sustain their safety, and give them the chance to live the self-directed lives they deserve.

Thank you for taking the time to hear our stories and for recognizing the critical importance of home and community-based services. I urge Congress to protect and strengthen HCBS so that individuals with disabilities, their families, and the direct support workforce can continue to thrive.

Sincerely,

Nathan Buckalew

Regards,

Nathan Buckalew

4055 Mercantile Dr

OR 97062

PENNSYLVANIA

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I know that I'm a capable adult who can and should live on my own with the proper support

Regards,

Kris Rhood

1004 Woodland Ave Apt 4

Sharon Hill, PA 19079

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to HCBS is the difference between stability and crisis for my family. As a disabled parent with limited income, these services allow me and my child to live safely at home instead of being pushed into unsafe or institutional settings. HCBS fills in the gaps that my disability and financial situation create — things like in-home support, medical care access, and the resources that allow me to keep our household stable.

Without HCBS, everything would fall apart very quickly. I would not be able to afford the basic medical and support services I rely on. My child's quality of life would suffer, and we would be at risk of losing our home or ending up in situations that are dangerous, traumatic, or completely inappropriate. These programs keep families like mine intact. They keep us functioning, healthy, and safe when there is no other safety net.

HCBS isn't a luxury — it's the foundation that allows me to live with dignity, remain independent, and continue caring for my child. Without it, the outcome would be devastating.me because

Regards,

Lynann Eller

724 Mastillo Rd

Hollsopple, PA 15935

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it provides a home environment and a family for people like my brother Dennis. The handicap are entitled to a community which is like home. My brother Dennis is very happy in the group home. Facilities don't provide the one on one care and environment for good care and needs of the individual. Facilities lack the personalized care and are breeding places for germs and disease.

Regards,

Neva Capezza

Cobbs Lake Preserve, PA 18436

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because as a sibling of an individual with intellectual disability, I feel that this is the best situation for my brother and the entire family. The impact of programs like Medicaid HCBS have had a tremendous impact in our lives, as my brother would not thrive in other situations. His life would be miserable. He enjoys interacting with family and friends and other situations would increase his anger and depression.

I feel that the benefits of the HCBS is not unique to our family and that most other people with disabilities would prefer these programs. Contiuations of these programs also have impact on the society as a whole.

Regards,

Guissou Dabiri

1311 Grenox Rd

Wynnewood, PA 19096

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it promotes well being for all.

Regards,

Regina Brooks

308 Friday Rd

Pittsburgh, PA 15209

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Medicaid Home & Community Based Services matters to my family because both my spouse & I are disabled Americans with my spouse recently being of retirement age. We are just now learning about & utilizing Home & Community Based Services to navigate Health, Transportation, Home & Nutritional needs which is & would be helpful & beneficial to my family. Especially with the economy as it stands at this stage of our lives we need as much help as there is to offer. Things are getting pretty scary with this schitzo Trump at the helm creating all the inhumane chaos he can.

This should have never been able to happen in our country

Regards,

Tina Roberts

300 S Main St

Clarendon, PA 16313

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

People with disabilities and older adults deserve to live with independence, dignity, and connection to their communities. Programs like Medicaid home and community-based services (HCBS) help make this possible by helping people stay in their homes, attend school, work, and participate fully in their communities.

Regards,

Dumitru Neagu

9968 Dungan Rd

Philadelphia, PA 19115

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because this is the most important thing that will keep children from being institutionalized. Histroy has already proved that institutionalization does not work

Regards,

Hiren Ardeshna

5010 Tomahawk Dr

Collegeville, PA 19426

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my grandson is autistic and need support to function in the community.

Regards,

Paul Harvan

1620 Dogwood Rd

Flourtown, PA 19031

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a daughter who has Down Syndrome. We thank God that there are programs that she can attend to get her out of the house so she can learn to be independent. To be able to depend on funding to help us pay for this service that we couldn't afford on our own. My husband and I are 67 years old and are retired. But we still have to work because our small home is not paid off. It should have been but we had to borrow against it for a new roof then windows and before you know it we owe another $45 thousand dollars. With the cost of groceries sky rocketing, gas, home and auto insurance as well as utilities we don't have anything left to help our daughter get out into community programs. We need this funding. We need her Medicare and Medicaid. You people have the power to help all who are struggling and in need.

Respectfully, Denise a concerned parent who needs you!

Regards,

Denise Mendoza

2616 Linden Ave

Aliquippa, PA 15001

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a daughter with disabilities

Regards,

Richard Sommers

2026 Woodside Ct

Allentown, PA 18103

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because at age 98 I am very involved in the life of my city and emotionally invested in my community, but I am homebound. HCBS helps make this possible by helping me to participate fully in communal life.

Regards,

Hope Punnett

6635 Wissahickon Ave

Philadelphia, PA 19119

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter is on Medicaid and it covers all her medications and therapies at school. It also covers her doctors visits. She has a heart condition and is autistic.

Regards,

Melissa Giannini

275 Roberts Dr

King Of Prussia, PA 19406

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

I am writing on behalf of my daughter, Colleen who is 44 years old and profoundly intellectually delayed. Medicaid HCBS has allowed her to attend an adult day program for the last 23 years. At her program she participated in community activities such as outings to libraries, parks, senior living centers, and volunteered at a pet shelter. She is also taught daily living skills, engaged in an exercise program as well as a therapeutic equine program.

Her program has allowed her to grow as a person and provided her a sense of accomplishment and improved her self esteem. Medicaid HCBS has helped her to become the happy, well balanced adult she is today despite her disabilities.

Thank you,

Richard Rothwell

Regards,

Richard Rothwell

115 Shippen Rd

Erdenheim, PA 19038

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because no one should be alone. Older people and people with disabilities depend on others for care and companionship. Their families rely on assitnace from others because it takes a lot of time and effort to care for the elderly and disabled.

Regards,

Debra Wontor

3304 Hemlock Farms Rd

Hawley, PA 18428

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my brother is 55 years old and he has special needs. We never thought he would be able to live independently, but through funding, he was able to move out of my parent's house and live on his own! My brother is a dishwasher. He works hard, but with the minimal pay he receives could not afford to live on his own. He does not collect SSI because he chooses to work, so the help he receives with his rent each month is a game changer! He is so proud that he can live on his own. I am his only sibling. My Dad died and my Mom is now in memory care. Without this help, I don't know where my brother could afford to live. His funding for the past 20 years through Community Options has changed the quality of his life and of our family's life. We couldn't be more grateful for this support and he needs it. How else would he survive if something happened to me and he was all alone? Community Options provides staff to take him to doctor appointments in addition to subsidizing his rent. I don't know what we would do without this support!! Please keep funding for housing! Older people with disabilities need your help.

Regards,

Kelly Powers-Zollers

539 Moreboro Rd

Hatboro, PA 19040

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because people with disabilities and older adults deserve to live with independence, dignity, and connection to their communities.

Regards,

R S

7 Valley View Dr

Mountain Top, PA 18707

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because as a parent of an individual with intellectual disability and Epilepsy, I understand how much difference the family living together and watching over my daughter can make. The community supports available to her make her happy every day.

Regards,

Joseph Vedam

2230 McArthur Dr

Hatfield, PA 19440

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because the people in the community living situation deserve the fullest life they are capable of

Regards,

Mary Judge

847 N Bromley Ave

Scranton, PA 18504

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we all need to listen

Regards,

Suzanne Lamborn

225 Lees Bridge Rd

Nottingham, PA 19362

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows the caregivers to be able to participate and assist their love ones with the everyday care. When a caregiver participates or has their love one near them, there is such a piece of mind that comes with it; as you know that they are not lacking for any essential thing or being abused or mistreated. It costs much less to keep them at home or near you than in a group home or nursing home. We just want support and the waivers provide that.

Regards,

Xiomara Rojas

4015 Greenwood Ave

Boothwyn, PA 19061

Submitted on Thursday, December 4, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows participants to feel included and gives them the opportunity to learn new life tools

Regards,

Tamicka GROOMS

220 E Fairview St

Allentown, PA 18109

RHODE ISLAND

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because - they are truly a GOD-send for millions of elderly & disabled citizens that need the vital assistance of trained CNAs and advocates to maintain a dignified presence in our communities - also it helps to keep aging and disabled Americans out of EXPENSIVE Nursing Facilities - use resources effectively! - Thank You

Regards,

John Lancellotta

32 River Ave

West Warwick, RI 02893

Submitted on Sunday, November 30, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because reasons.

Regards,

Deanna Coleman

118 Tobey St

Providence, RI 02909

SOUTH CAROLINA

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son is 40 years old and unable to live on his own, and I am unable to live forever. Him being in a group home in the community has given

him independence and security to me for his well-being for beyond when I am no longer here. As a parent this is a true gift from God to not have to worry about what will happen to him when I am no longer here. Thank you & God bless

Regards,

Victoria Jackson

31 Garden Gate Cir E

Hardeeville, SC 29927

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, as I grow older, I may very well need it. I have physical disabilities that sometimes affect my mobility and I suffer from long-term PTSD and major depression.

While I am able to maintain my own home now, I am close to 80 and realize that I may have to make other arrangements in the future.

Community living would give me more company and conversation, and possibly, more intellectual and activity outlets that may help me maintain my mental and physical wellbeing. I saw this with my father when he needed to live in a community setting. It was far better than his isolated existence at home alone.

I hope you will also consider the many, many people who cannot live on their own at any age, but who deserve the most supportive and least restrictive home setting possible to meet their needs. Everyone should be able to develop their interests and abilities to the greatest extent possible.

Regards,

Barbara Sloan

3028 Minsteris Dr

Conway, SC 29526

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I attend a program three days a week which is possible through HCBS . I have friends there and I have fun. The HCBS provides me with transportation and I can do this without my parents which makes me feel more independent .My mother is helping me write this she worked for this program as a Medicaid service coordinator and helped a lot of people finds jobs and live a happy life

Regards,

Nicholas Gillard

158 Myrtle Trace Dr

Conway, SC 29526

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a son who is disabled who is on Medicaid and needs these organizations and services in order to survive, as well as manage his day to day living. Honestly without Medicaid and these community services is would just be devastating to us as a family.

Regards,

Barbara Darnell

1816 Appaloosa Dr

Sumter, SC 29154

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my brothers are 55 yr old twins, and both cognitively disabled. They absolutely need support. They lived in a community in central FL and were so happy and proud. Their social needs were met, they had clean acceptable living standards. My aging mother can’t do this at 81. I moved them to live with us in SC, they miss their independence, they feel depressed and just want to live in a community again. They need to be safe, gated community where they can’t be taken advantage of. We

need this in Upstate SC. They need ride support, they need respite care. They are awesome but unable to do this for themselves. Supported, Independent living in apartment communities especially created for this population.

Regards,

Kristina Duff

320 Carrollton Ct

Greer, SC 29650

Submitted on Tuesday, November 25, 2025

Dear Members of the Special Committee on Aging,

My daughter has received various in-home services since her diagnosis of an in-utero stroke resulting in hemiplegia and cerebral palsy. It is unfortunately often that the doctor at the time of diagnosis will tell parents that their child will not be able to talk, walk, work, live independently, etc. It is only though home-based services including respite for the parents that a family is able to cope with the challenges that come for the rest of the parents and childs life. It has been absolutely invaluable for us.

Regards,

David Cottington

Rock Hill, SC 29732

SOUTH DAKOTA

Submitted on Wednesday, November 19, 2025

Dear Members of the Special Committee on Aging,

Medicaid and community-based services matters to my son and me because we both receive Medicaid. Also I have United Healthcare and Medicare. My son has ADHD, autism, depression, and anxiety. I've been struggling with my mental health since I was a teen. We have case managers, home health that does home visits. Last May, my son was at behavioral health urgent care for a week because he wanted to end his life. There are not a lot of programs like bigger cities have. There has been two shootings in our town. The last one happened on Halloween and another last year. Both victims didn't survive.

Regards,

Joy McGeorge

Huron, SD 57350

TENNESSEE

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because this affects my brother. He is disabled, and needs to have these agencies to help him live his best life. Thank you!

Regards,

Amy Wood

505 Vandever Rd

Crossville, TN 38572

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I can continue to live independently and interact with the community and continue to continue my advocacy with family members and the person's served in the agency in the state of Tennessee

Regards,

Shaun Fritts

3965 Pryor Rd NE

Cleveland, TN 37312

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my sister is special needs due to anoxia at birth.For many years she lived at home with our family.At around age 20 she had days when she wouldn’t go to her day program.At this point the rest of the family all had needed jobs and college that couldn’t be missed every day.We found a live-in program for her and reluctantly moved her into it.While this was very hard to have to do this their was really no other option.This program changed her life-gave her purpose and essentially another family to care about her.We visit frequently and while she loves our visits this has become her home and safe haven.She is now 72 years of age and would be very upset if this group home situation changed.I believe this program has been a godsend for her and our family as well as th others in this program and their families.

Regards,

Marilyn Bryan

7509 Twin Creek Rd

Knoxville, TN 37920

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because if you don't have a community, what is there? People are nothing without community. Medicaid is detrimental to millions of Americans within our communities. I care about my community, do you care about yours?

Regards,

Gavin Anteau

141 Withers Ave

Smyrna, TN 37167

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because IM DISABLED NEED HEALTH GYM EXERCISE , HEALTHY FOODS HEALTHY OVER ALL DIET AND TAKE CARE OF MYSELF

Regards,

Jerome Moses

200 Old Federal Rd

Madisonville, TN 37354

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we need to be there for each other.

Regards,

Frances M

332 Campbell Dr

Rogersville, TN 37857

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we all need care and support from one another.

Regards,

Amy M

332 Campbell Dr

Rogersville, TN 37857

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we need people.

Regards,

Susan Gilliam

410 6th St

Lawrenceburg, TN 38464

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because without Medicaid HCBS I wouldn't be able to stay in my home. I would end up more isolated than I already am. I would have to give up the few things and small pleasures in the world that really mean a lot to me, like my dogs and my many plants. These sound like small things that shouldn't mean so much, but when multiple chronic medical conditions have rapidly advanced and taken away everything that matters to you in life, the way you value and become grateful for the things that are left changes. I'm only 50. There is still a ton I don't have: I'm still mostly completely homebound since I don't have accessible transportation of my own, and some of my conditions aren't well controlled, so I still can't work at all because I'm unable to keep any sort of schedule. But I continue to work on bettering my health and try to find ideas for ways I might work again someday. I still have so many dreams and I want to make the biggest difference in my community and in the lives of others. People with disabilities - even multiple and severe ones like me - aren't worthless and we shouldn't be treated like we're invisible or our needs don't fully matter. Defunding these programs hurts society as a whole: Please, SEE ME! HEAR ME! I used to start nonprofits. I used to write things that educated people. I used to change the community I lived in in big ways. I could be that again. So many disabled people want this for themselves. I really feel like there should be

broader funding for these programs for ALL disabled people, and it saddens me that there isn't. I fought with my state for over two years to be able to get the help I do get, and I'm grateful, and I think it needs to continue. I still implore you to consider this and more. It's easy to view people who aren't the same with conditions you don't understand firsthand as throw away, but so many of us have things to offer society that is going entirely untapped because the government views disability the same as less than. We may be a protected class, but believe me, we know what others think of us. The reality is just that disability means different. Every single person gets help from somewhere. Disabled people should be allowed to continue that as well, even those who need the help provided through Medicaid HCBS. Thank you for reading my letter.

Regards,

Jennifer Kirila

Murfreesboro, TN 37128

Submitted on Friday, December 5, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because so many of our individuals with disabilities are getting older. Their parents and families are getting older. If the individual still lives at home with their parents the parents will need to find arrangements for the future when they will no longer be able to support their child. Having community living supports allows families to have the comfort of knowing their family member is being well taken care of.

Regards,

Amanda Tackett

208 Nancy Ln

Clinton, TN 37716

Submitted on Saturday, December 6, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because that is where all people live their best life!

Regards,

Kim Whitaker

266 Whitaker Hollow Rd

Rocky Top, TN 37769

Submitted on Saturday, December 6, 2025

Dear Members of the Special Committee on Aging,

Loren likes living in an apartment with a roommate. He is learning to be independent with day staff and night staff helping him with minimal instructions. Loren works 3 2 hours shifts 3 days a week putting pizza boxes together at Papa John's Pizza. Loren likes staff taking him out in the community to go to places he likes to go to. Staff is helping Loren stick to a gluten free sugar free diet. Without Medicaid Loren would not have staff at Emory Valley Center to help him.

Regards,

Loren Storch

284 Jefferson Ln

Clinton, TN 37716

Submitted on Sunday, December 7, 2025

Dear Members of the Special Committee on Aging,

I am the parent of a young man, 30, who has autism, an intellectual disability, ADHD and anxiety. He has extremely limited communication skills and intermittent but significant behavior issues. Community living matters to me because my son made it clear through his behavior when he was in his late teens that he no longer wanted to live with me and his father. He became a danger to himself, to us as his parents, to his twin brother, and others around him.

My son had been on our state's waiting list for Medicaid Waiver home- and community-based services for 11 years at that point, and he was fortunate at that crisis point to be enrolled in our 1915c waiver. But it took us two years to find a provider willing to provide supports to someone with his behavioral needs and close enough to our home that we could continue to be closely involved in his life and to remain in the town that he's lived in for 27 of his 30 years.

He has been in supported living for eight years now, and he's much happier. He still has meltdowns, but they are briefer and more intermittent. His staffers support him to do the things he likes to do, such as walk on our community's greenways and parks, swim at the local rec center, and visit the zoo and local museums.

My son requires 24/7 support, and he lives alone because of his behavior issues, so his supports and services are costly. I understand that, and I appreciate the fact that our state is providing these supports and service. But maintaining these supports requires a great deal of advocacy on the part of us as his family.

If drastic cuts were made to his waiver funding or supports, our family would face extreme difficulties. First of all, his father and I are in our late 60s, and physically unable to keep him safe or ourselves safe when he experiences a significant behavior incident. Second, his twin brother is now living in our home and has a 2-year-old daughter who is with us each weekend, and one of our autistic son's triggers is young children's voices and their crying. So it would be dangerous for his twin and our granddaughter if he were to lose his supports and have to move back home with us. We are not able to afford to pay for him a place to live with 24/7 staff. The Medicaid Waiver that he currently has allows him to live the life he wants in his own apartment, allows my husband and me to continue to work at our full-time jobs, and allows us, his twin brother and our granddaughter to live safely in our home.

Medicaid HCBS waivers are truly a lifeline for many of us. Please make sure funding is appropriate to serve the needs of people with disabilities.

Thank you.

Regards,

Janet Shouse

409 Crofton Park Ln

Franklin, TN 37069

Submitted on Monday, December 8, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I work with families that need support in their community to help their child reach their developmental milestones. Community programs and assistance help the families I serve gain more support and feel like they have a connection within their community.

Regards,

Paula Dickerson

106 Westcliff Dr

Harriman, TN 37748

TEXAS

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

Regards,

Monica Williams

8708 Mission Rd

San Antonio, TX 78214

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

If we didn't have community living, then we wouldn't have anything to do for special-needs people like us, and we wouldn't be anywhere today without it.Community living matters to me because

Regards,

Brandon Bunch

12943 SH 30

College Station, TX 77845

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter with Angelman syndrome non-verbal 23 mind of a 2 year old has needed her speech, occupational and physical therapy all her life. Specialists have done wonders from legs, scoliosis and disability dental. Needed anesthesia for all cleanings when approved. Recreational and music is also a big part of her life. When she visits movies, gyms, pools makes her and others smile too.

Regards,

Gina Velazquez

1506 Seminary Ridge

Garland, TX 75043

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a daughter with special needs

Regards,

Brenda Herrera

8017 San Jose Rd

El Paso, TX 79915

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

My daughter has Autism and Seizure Disorder. She is non verbal and lacks 6 out 6 basic living skills. She requires care 24X7, Care for her is not a choice, it is a necessity. At best, she should qualify for Maximum funding, at least is her current Medicaid benefits. She is 30 years old and has not able to even tell you when she is sick or if she is in pain. I am writing today for those individuals who cannot advocate for themselves. I have paid my fair share of taxes all of my life but Texas believes in Corporate Welfare and gives Millionaires massive tax breaks.

Regards,

David Gibbs

449 Vista Noche Dr

Lewisville, TX 75067

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I want crime free neighborhoods.

Regards,

Garry Kramchak

8542 Dairy View Ln

Houston, TX 77072

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

my son is 34 with cerebral palsy and we rely on community living it makes him feel like he real is independent and and it make him smile and full filled He makes friends that these kudos gave a hard having. There really is a need for this in adult disadvantaged kiddos

Regards,

Kim Kruckenberg

1902 Elysian Flds

Austin, TX 78727

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

I am a behavior analyst that works with adults with special needs. I see first-hand how this population and their families/providers live. Because behavior support was not available to these individuals when they were younger, learning takes more time. Think about how long

it takes you to learn something as an adult vs. when you were a child. We were sponges when we were little! The different programs that are offered by the state literally change these people's lives. They allow them to learn new skills and decrease different problem behaviors. It let's them become as independent as they can be and less likely to need more support when they are older. In many ways, this is a lost population and Medicaid allows them to learn and grow and live.

Regards,

Beverly Smith

2427 Facet Oak

San Antonio, TX 78232

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter has Cerebral Palsy and needs the assistance even for the smallest things in life!

Regards,

STEPHANIE FLORES

517 Wickes St

San Antonio, TX 78210

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my sister has had 20 strokes a heart valve replacement three stents she has diabetes and liver and kidney problems. Without Medicaid she would be kicked out of her Care facility and die. She has been a great contributor to societies and EMT and a respiratory therapist she deserves to live out the rest of her life!

Regards,

Wayne Stalsworth

147 Kickapoo Trail

Seguin, TX 78155

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have relatives who just retired and don't know how to live their lives. Also, for folks who are old & disabled, it's not that easy to find work or even apply online. Folks get rejected all the time due to them either being really old &/or disabled & the economy sucks.

Regards,

Yasmeen Almasri

1406 Broadmoor Ln

Irving, TX 75061

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters

Regards,

Luke Fain

2705 Regents Park

Austin, TX 78746

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it has been a total failure for this family. My son was born in 1964 with IDD and hyperactivity issues. At this time, help was inly available through State Supported Living Centers. James resided at Lufkin SSLC until age 54 when he passed from liver came. My nephew was born in 1974 with the same issues. Aaron died

in 2007 as a result if mistreatment in a group home. My grandson was born in 1988 with the same issues. All three boys were non-verbal. In 1990 we learned of the genetic cause through intensive testing by a geneticist. The grandson lived in 3 group homes by 2 different providers … disaster all the way around. He indicated 3 times he was sick and wanted help. The provider refused. His mother - a nurse - picked him up and realized he had a fever. He was taken to the ER where he was diagnosed with pneumonia and was placed in ICU fir a week. There were many other negative happenings. With the next provider, grandson acted out so the staff called the police and grandson was taken to the county hispital's psychiatric ward. Grandson was placed in a hime with the county's MHMR local authority … he hit staff and the police were called … he was faken to the city jail and then to the county jail. This family is expert in care for IDD persons .. the Arc IS NOT.Staff at group homes or cimmunity himes are nothing mire than glorified baby sitters. They have no specialized training. The turnover horrendous. There are ni meaningful iversight nor inspections if "group homes". The staff at State Supported Living Centers have superior training. I can assure you that communities do not welcome group homes and their residents. The Arc is not a friend.

Regards,

Lyndal Waddy

Mineral Wells, TX 76067

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because without it I would surely be dead to be quite frank.

Regards,

Michael Lassiter

200 Murls Lake Rd

Weatherford, TX 76085

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we all might need it one day - you never know.

Regards,

Shelby Scarbrough

215 Post Office St Apt 1007

Galveston, TX 77550

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I feel ver isolated.

Regards,

judith zwarun

5108 Avenue G

Austin, TX 78751

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

How do programs like Medicaid home and community-based services (HCBS) impact your life? What would happen if you didn't have them? You act as if this is going to happen; it HAS happened. I am on SSDI I HAD Medicaid. My husband now qualifies for disability as well. Our actions caused neither, and we were forced to use these services, which you act as if no one had paid for in advance. Losing Medicaid has stopped all medication I was on, medications I needed to have a semi-everyday life. I have had to re-enroll in school to finish a degree I was unable to finish on medications, now, trying without and without funds. We are concerned about people who are worse off than we are, people older and in worse health, not only locked up, but in hiding and unable to get their medical concerns addressed. I am disgusted by what America has become. We all have failed her.

Regards,

Lori Dugger

2424 Texoma Pkwy Trlr 67

Sherman, TX 75090

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have an older brother who is living with I/DD and AU.

He was raised in a middle class family of 7 to be as included and involved with society as possible. He struggled with learning and managing his financial affairs. He was able to obtain employment but lost it due to inability. Later, he was placed in employment, which was successful for 37 years. He like all adults need automomy and independence. At first he lived at the YMCA, where he became a victim. Later, he lived in supportive housing which is where he met his first ever friend. When that fell through, he and this friend lived in a condo that the parents provided. This was great for the guys but hard on the parents, especially because by now, our mother was a single parent. Family lived close and could do check ins. He took public transit to work each day.

If he had qualified for HCBS that would have made my parents fainancial future so much more secure and it would have offered him the community he had never had.

Blessedly, now he is in a supportive, rural community with others just like him. He is accepted and somewhat of a leader. Best of all , he is cared for physically, spiritually and socially.

Sadly, our state has long waiting lists for any HCBS services. While he qualifies, he is about 15000 on the lists.

This impacts my sole living parent tremendously and our family juggles a great deal to keep him in his dream environment where he is so happy. We hope to continue supporting him until his number comes up, but we all have limits ourselves. My mother frankly, just does without.

Please think of these individuals and their families. They need dignity, respect and safety. Most of this population is subject to manipulation and predation. Help us keep them happy, healthy and safe.

Regards,

Elizabeth Chamberlain

1714 Pecan Park Dr

Arlington, TX 76012

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because IT IS ONLY PLACE SENIOR CITIZEN CAN LIVE ECONOMICALLY SAFE

Regards,

Roy Moran

513 Rosedale Blvd

Georgetown, TX 78628

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

I have multiple issues & it requires a community to deal with them!

Regards,

Jack Jacobson

2739 Babcock Rd

San Antonio, TX 78229

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because i'm a quadriplegic person who cannot do anything for myself other than brush my teeth and feed myself. Medicaid's financial support allows me to have a 24/7 caregiver. Without her I would die.

Please note I live a very full life participating in numerous civic and religious communities. Let me encourage you to view this following video on how 14 people with Spinal Cord injuries live a fulfilling life.

YouTube

Type in: From Where I Sit UAB

Thank you for your support!

Chuck Fattore

Regards,

Chuck Fattore

18102 Mable Pond Ln

Richmond, TX 77407

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because our special-needs daughter with profound IDD, who lives in a group home, life depends on it! She is 24/7 total care. There's NO way one person could take care of her. It takes a team. Plus we as her parents are getting older and worry about her future. She has lived in a group home for 24 yrs now. It has been a GOD send for her and us as her parents

Lately, I've been extremely concerned with all the shutting down of HCS group homes due to budget cuts and rising costs of living. I have tried contacting all I know to make sure her rights are not violated and to be an advocate for her and all the others who depend on these services. We HAVE to be their voice!!

This DEEPLY CONCERNS me. I have physically seen the care of these people decline due to limited resources and staffing. It scares me actually for their future! They are the ones who suffer and they dont deserve to.

Please Please....

We DESPERATELY NEED you to come along side us and advocate to keep these HCS group homes and services opened and going strong to give these people proper care and housing. To keep them connected with their community and family and drs.

These are legal US citizens who depend on you! This IMPACTS their lives tremendously!

They need and rely on Medcaid and HCS as a means to survive and get the help they need.

They didn't ask to be born like this and they deserve to be taken care of in the best way possible!

Thank you for your ear and time!

I pray you find it in your heart to be the Biggest Advocate and Voice for these precious people and keep these services going strong!

Regards,

Linda Cox

4025 Oakhurst Dr

Amarillo, TX 79109

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living and home health matters greatly to my family because it has allowed my son to go to college, get a degree, be with his peers, work, and be an active member in his community.

The personal care wages in my state are currently too low ($13 an hour), so it prevents me from hiring enough help to be able to work too. The cost of living is sky high where I live. The costs of being in the community living a full happy life vs an institution is 5 times more, so it is a win win for all. Money follows the person is smart, and actually it started in Texas to save a lot of money which it does. If we prioritize care attendant wages, parents can work, and many with disabilities (but not all) can work as well. This brings in more taxes and happier and healthier people. There should be no asset limit (currently 2k total asset allowed), and they should be able to keep their Medicaid waiver services. Current federal law forces poverty on people with disabilities. We can fix this!

Regards,

Jessica Rothe

100 Cantle Cv

Liberty Hill, TX 78642

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it's important for all human beings to be together to learn, share, care, compassion, and a basic need.

Regards,

Joelene Moore

6801 Manor Dr

North Richland Hills, TX 76180

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, No one knows Our daughter better than her Family and friends. Felicia has been able The program (CLASS) has been able to provide such care to partake in community activities and go out with the help of Family and friends and Attendants. Please take note that by taking away such programs, you are refusing to help Felicia from having individual care. Think about your own family, would you allow anyone else in nursing homes to act accordingly. People in nursing homes are abused and neglected. The help We receive is the best possible solution. Please DO NOT TAKE THESE PROGRAMS AWAY. They are very beneficial to the Care and Love received by family and friends and attendants. This is the ONLY WAY THAT FELICIA CAN COMMUNICATE WITH THE OUTSIDE WORLD. Felicia is not just some number on a page. She is living breathing Soul who deserves to be heard.

Regards,

Susan Ponce

2418 Greencrest Dr

San Antonio, TX 78213

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have been working with children and adults with intellectual disabilities for many years. Most will not be able to integrate into our society. Having a place to live with people like themselves makes their lives much better. They can relate with their neighbors and function closely to them. Most places that provides those services have work opportunities for them. One place I work with has jobs that pay. This allows the individual to have a job, earn money, and be able to buy things on their own. They are not subject to the kind of behavior that degrades and minimizes them as human beings. It's not something for children who need to be with their parents or other caregivers until they are more mature and have a desire to have their own life. The government, at every level, needs to be supportive of those programs. Having a life in which you feel accepted and supported is essential to have a life than one feels good about.

Regards,

Michael Jones

14626 Hazy Ridge Ln

Cypress, TX 77429

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it’s what makes our society.

Regards,

Carlos Alvarez

7920 San Felipe Blvd

Austin, TX 78729

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

My name is Kristen Jones, and I live in Round Rock, Texas. I am a person with quadriplegia resulting from a spinal cord injury, and I use a power wheelchair for mobility. I rely on Medicaid Home and Community-Based Services (HCBS) through Texas’ STAR+PLUS

program, including personal care attendant services that support my activities of daily living. These services allow me to live safely and independently in my community.

HCBS enables me to live a full, self-directed life. I work full-time for the State of Texas, teach as an adjunct professor at several Texas universities, hold a PhD, own my home, and serve on nonprofit boards and my homeowners association. I have had the same personal care attendant for 17 years—continuity of care that no institutional setting can replicate. This stability prevents health complications, emergency hospitalizations, and ensures my daily needs are met safely and consistently. I purchased my own home five years ago, and HCBS allows me to maintain housing stability and remain an active, contributing member of my community.

Even with a full-time salary and a second job, I could not afford the cost of care I require. My personal care attendant services alone cost nearly $50,000 per year, not including additional medical supplies that private insurance does not cover. HCBS is far less expensive than institutional care, which nationally costs two to three times more per person annually. Without HCBS, I would likely be forced into a nursing facility—not because I need that level of care, but because the supports that allow me to live independently would no longer be available. Nursing facilities often provide poor quality care due to low reimbursement rates, chronic staffing shortages, and limited capacity to meet complex needs. These risks are not theoretical; they threaten the health and even the survival of people with significant disabilities. Moreover, ongoing Medicaid cuts have made it increasingly difficult for nursing facilities to accept Medicaid recipients, leaving people with nowhere safe to go.

HCBS allows me to work, pay taxes, teach, and contribute to my community, strengthening both families and the broader economy. It prevents unnecessary institutionalization, reduces long-term Medicaid expenditures, and allows people with disabilities and older adults to remain engaged and productive in society. These programs stabilize communities, enhance quality of life, and save taxpayer dollars.

I am fortunate to receive these supports, but thousands of Texans remain on multi-year waitlists for the same services. The need is urgent, and the return on investment is clear. I urge Congress to ensure sustainable HCBS funding, strengthen reimbursement rates, and expand access so that all Texans who need these services can live with dignity, independence, and safety.

Thank you for taking the time to hear my story and for recognizing the critical importance of Medicaid Home and Community-Based Services.

Regards,

Kristen Jones

2800 Joe Dimaggio Blvd

Round Rock, TX 78665

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because after caring for family members placed in Nursing homes I have no desire to be there. I want to receive care in my own home and transferred to Hospice when the time comes.

Regards,

Marilynn Reeves

995 Horseshoe Lake Rd

Iowa Park, TX 76367

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows my 21 yr old daughter to access therapies that help be able to be a part of community. She loves being social and going out to community events as well as going out to eat and shopping.

Regards,

Sabrina Cantu

3806 Enclave Mist Ln

Richmond, TX 77469

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it gives people with disabilities and older adults independence, dignity, and connection to their respective communities.

Regards,

Evangelina Quintana

108 New Orleans Dr

El Paso, TX 79912

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter can live with me instead of an institution or Nursing home.

Regards,

Donna Reed

9 Red Deer Ln

Spring, TX 77380

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter, Jennifer McKown, was one of the first persons to get into the Texas Medicaid Waiver Program known as HCS in 2000 at the age of 21! She has lived at home and learned to cook, wash clothes, clean house and become a valued member of our community. She is active at church and in Daughters of the American Revolution of which I am a member also. I have provided her transportation to doctors, dentists, dances, trips to see family and friends and all kinds of activities she would not have gotten had she not been supported by HCS. Through HCS she was able to get speech therapy and learn to read on a 5th grade level. I believe that without the support she has received from Lakes Regional MHMR with Pace Opportunities being the provider and now Concho Valley MHMR with Daybreak being the provider, she would not be the happy, sweet, active and fun loving adult she is today.

Regards,

Pamela McKown

4157 Pendleton Pkwy

San Angelo, TX 76904

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my 23 year old son is able to live with us and continue to be involved in community activities and be surrounded by family. If he were in a facility, he would be at least an hour away from those who know and support him best.

Regards,

Kristy Pierce

Navasota Dr

Plainview, TX 79072

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, my daughter has been suffering for too long.she was born breach 38 years ago. She had to wear a brace between her feet at age 6 months. She has been in a wheelchair since age twenty. She has been forced to be a human guinea pig most of her life. She is now having cardiovascular issues.

Regards,

Michael Grasselli

2522 E Trinity Mls Rd

Carrollton, TX 75006

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am the caregiver of my 32-year-old profound autistic son who lives with us in our home. Currently there are no HCS group homes available for him to live in the staffing shortage in these group. Homes are very low the attendance only make in Texas $13 an hour so they're not very motivated to stay hired or have the training that's needed to be a Direct Care Workers.We are worried nonstop about what will happen to our son when we pass away. We are not wealthy and have no family to step in as we age. Currently there are no devices for the aging profound autistic s adults. Thank you for you help

Regards,

Tammy Doyle

1904 Canvasback Ln

Flower Mound, TX 75028

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

How do programs like Medicaid home and community-based services (HCBS) impact your life?

What would happen if you didn't have them?

MY NAME IS TAMMY LOUISE ATKINS RECORD WEAVER, AND I AM A 65 YEAR OLD DISABILED WOMAN, PHYSICAL AND MENTAL DISABILITIES.. I WAS PUT TO WORK AT THE AGE OF 5 YRS OLD, I WORKED HARD, HONEST, BLESSED, AND THANKFUL. I WORKED MANY, MANY DIFFERENT JOBS, OWNED A COUPLE OF MY OWN BUSINESSES, ALWAYS WORKED HARD AND DID EVEN MORE THAN JOB DISCRIPTION, MADE SURE I DID EACH AND EVERY POSITION TO PERFECTION, EVEN IF I HAD TO EDUCATE MYSELF ON EVERYTHING IT CONSISTED OF AND BEYOND. I HAD 1 BIOLOGICAL SON, ADOPTED 2 DAUGHTERS, AND 1 SON, ALONG WITH COUNTLESS NIECES, NEPHEWS, AND MANY OTHER FOLKS KIDS, RAISED THEM TO DO THE SAME. THEN SUDDENLY I LOST MY BEST FRIEND, AND MOM, THATS WHEN I LOST ME, IN A SWIRL OF OLD ISSUES OF RAPE, JOB SEXUAL HARRASSMENT, GANG BANGS, BEATINGS, MUCH, MUCH MORE WHICH I HAD BLOCKED AS IF NONE EVER HAPPENED, UNTIL I LOST MY MAMA. THATS WHEN MY MENTALL DISABILITIES HIT ALONG WITH ALL THAT I HAD BLOCKED AND PULLED ME DONE INTO THE DARKEST OF DARK I NEVER IMAGINED. MHMR WAS THERE TO HELP ME GET STARTED BUT JUST NEVER BEEN ABLE TO GET ME BACK AGAIN, STILL. DURING THAT

TIME I HAD BEEN SENT TO A PAIN MANAGEMENT DOCTOR WHICH SEEMS HE WAS ONLY CONCERNED WITH PRESCRIBING DRUGS, AND MORE DRUGS. HE ALSO PERFORMED INJECTIONS WHICH WERE OFTEN UNTIL THE LAST ONE WHICH CRIPPLED ME WORSE THAN I HAD EVER BEEN. I WAS INFORMED BY THE YOUNG MAN THAT INJECTED DRUG TO PUT YA ASLEEP FOR HE / DR. DIAMOND DID HIS INJECTIONS, BEFORE HE PUT ME TO SLEEP DR. DIAMOND MADE SEVERAL SEXUAL, RUDE, VULGER COMMENTS TO ME, THATS WHEN I FLEW OFF AT HIM W/O THINKING AND LET HIM KNOW HOW DISGUISED I WAS, AND PISSED, THATS WHEN HE KNOTED TO THE BOY AND ONCE I WAS OUT DR. DIAMOND SAID THAT HE WOULD FIX ME REAL GOOD, THATS WHEN HE INJECTED ME IN WRONG PLACE, INORDER TO CRIPPLE ME. THIS WAS TOLD TO ME A FEW DAYS AFTER, WHEN HE CALLED AND INFORMED ME. I COULDN'T STAND, WALK, OR ANYTHING AT ALL. I FINALLY WAS ABLE TO CRAWL AROUND ON MY HANDS AND KNEES, AND MUCH LATER I FINALLY GOT TO BE ABLE TO USE A CAIN, AND STILL TO TODAY. HAD I NOT HAD COMMUNITY SERVICES, MEDICAID, MEDICARE, ETC I WOULD HAVE COMMITTED SUICIDE, BUT WITH THE VARIOUS SERVICES THSNK GOD I HAVE BEEN ABLE TO GET AND CONTINUE TO HAVE HELP, GET TO SEE DOCTORS, MY MEDICATION, FOOD, MUCH MORE THAT W/O I WOULD NOT HAVE KNOW ABOUT OR BEEN ABLE TO HELP ME NOT HURT SO BADLY, EAT, BATH, HAVE A ROOF OVER MY HEAD, COUNSELOR TO WORK WITH AND ALL THE SERVICES I HAVE HAD TO RELY ON EVERY DAY. IT HAS BEEN HARD TO BE A WORKAHOLIC, 6-7DAYS A WEEK, 12-18 HOURS A DAY, DOWN TO NOTHING. THE MANY KIDS I RAISED DON'T HAVE, WANT, OR CARE IF I AM ALIVE OR DEAD, IF I HAVE FOOD, PLACE TO LIVE, BILLS PAID, OR HAVE ANY KIND OF HELP. THEY DON'T CALL, TEXT, VISIT, BRING MY GRAND KIDS TO VISIT, IT IS LONELY, DARK, SCAREY, AND FEEL ABANDONED. WITH COMMUNITY SERVICES I HAVE MEALS ON WHEELS THAT BRINGS A MEAL DAILY, CHECK THAT I AM OKAY, EVEN HAVE A SHORT VISIT & CONVERSATION.. I AM BLESSED, GRATEFUL, THANKFUL FOR WHAT ALL I DO HAVE BUT LATELY THINGS ARE GETTING EVEN MORE SCAREY , WITH THE TALKS OF CUTS TO THIS, THAT, AND ALL. I JUST GOT OVER HALF OF MY SNAP BENEFITS WHICH IS CAUSING MORE STRESS ON HOW I WILL BE ABLE TO CONTINUE TO LIVE AT ALL, I HAVE AN EMOTIONAL PET, BEST FRIEND, 24/7/365 TO KEEP ME COMPANY, MAKE ME SMILE, &WORKS SO HARD TO KEEP ME FROM WORRYING, SCARED, CRYING. THAT CUT WENT TO THE BONE, AND IF YALL ALLOW ANY MORE CUTS, YOUR BASICALLY SAYING GO AHESD AND DYE BECAUSE EVEN THO YALL VOTED US IN TO PROTECT US, IT IS LOOKING LIKE WE DON'T MATTER AT ALL, INSTEAD THE WELL TO DOS, THE HIGHER UPS, PRESIDENT AND HIS LITTLE BUTT KISSERS ARE THE ONES THAT ARE BENEFITTING WITH OUR LOSES, THAT IS NOT THE WAY OF USA, AMERICA. SOMEWHERE ALONG THE WAY YALL GOT LOST AND SELF CONSUMED TO GET ALL YALL CAN AND THE HELL WITH US.

SO PLEASE STOP, THINK, LOOK AROUND, LOOK AT WHAT IS HAPPENING, TAKEN AWAY FROM THE VERY FOLKS YALL STATED YOU WOULD HELP AND PROTECT BUT INSTEAD WANT TO TAKE FROM US TO GIVE TO A DICTATOR WANNA BE. PLEASE I PRAY AND BEG OF YOU FOLKS TO DO THE RIGHT THING FOR US ALL, EVEN YOURSELVES CAN BE IN OUR SITUATION AT ANY POINT AND TIME.

PLEASE OPEN YOUR EYES, EARS, HEAD, & HEARTS AND DO AS YOU FOLKS ARE SUPPOSE TO AND HELP AND PROTECT US ALL NOW AND IN THE FUTURE. I PRAY THAT THE LORD TOUCHES EACH AND EVERY ONE OF YOU FOLKS AND CORRECT THESE ISSUES , STOP CUTTING US TO DEATH, AND PROTECT US ALL.

GOD BLESS YOU AND YOURS,

TAMMY WEAVER

D.O.B. 08/01/1960

903-487-8326

1816 N STATE HWY 91

APT 316

DENISON, TX. 75020-0003

texas_t_sunshine60@outlook.com

PLEASE I BEG OF YOU ALL HELP & PROTECT US.....

Regards,

Tammy Weaver

1816 N State Highway 91 Apt 316

Denison, TX 75020

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it's a choice

Regards,

Steven Rosenberg

2424 Parkview Dr

San Angelo, TX 76904

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a 24/7 caregiver to my dementia mom since 2014. I had to quit my job 3 years ago due to BOTH my parents getting sick. Three months after my job loss, I lost my dad, non dementia.

I have no idea at my age 60 how I'm going to manage my life after being a non paid caregiver.

Regards,

Darlene Day

8400 Palo Duro Ct

Fort Worth, TX 76116

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because every older relative I have deserves a safe and respectful place to live and the means to do so

Regards,

Mireya Dominguez

3106 Duval St

Austin, TX 78705

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps me be independent. My granddaughter is high functioning autistic with anxiety disorders and has asthma. She has had 2 jobs. One through DARS, Workforce Solutions with Chuck E Cheese.

The job coach did not stay on site with her. The place made her work 8 hours without a lunch or breaks during her shift. Second job with Party City made her wear a mask during Covid. She almost passed out due to having Asthma and couldn't breathe. So she is unable to work. She was on SSI when she was 8 or 9 yrs old . She was kicked off . We have tried getting her back on SSI due to her being unable to work. She is turned down each time. SS says she doesn't qualify. When we go to the SS office we have been told she can't get SSI because she is white by 2 different people. My granddaughter is half white and half Mexican.

Regards,

Shari Joel

4022 Brookmoor Dr

Arlington, TX 76016

Submitted on Wednesday, November 26, 2025

Dear Members of the Special Committee on Aging,

CoI was a stressed out single mom trying to work a full time job and a second job I could do from home. I had a stroke at the age of 46 which left me paralyzed. I didn't have insurance at that time, but there was a program called CBA program, Community based assistance. Without that help I don't know what I would have done. It provided the means for me to live in a nursing home over the years.Community living matters to me because I still need assistance. I received therapy in the nursing homes and I made some progress, but need more help. because I'm still paralyzed and with age comes new problems. Please don't remove help to those like myself otherwise we might all be paralyzed sleeping on the ground which I can't get down to the ground or get up from it.

Regards,

Donna Buckman

2300 Lee Trevino Dr

El Paso, TX 79936

Submitted on Monday, December 1, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we are 86 & 81. We need to be able to be near friends and family for support. We cannot get Medicaid even though our income seems to qualify. He has dementia and is totally incapable of caring for himself. Also, he has COPD, heart problems and is incontinent. I'm also a heart patient with diabetes, Dystonic tremor and 40+ allergies including gluten and nitrate. He was a minister 67 years and I was a chef. Normal and responsible lives but now we have to decide do we eat healthy food or put gas in the car so someone can drive us to the doctors appointments or, God forbid, do we need a heart medication we can't afford. If so, we beg drs for samples.

If not for family and friends, he would not have diapers to keep him comfortable between up to 6 baths a day.

Not because we are better than anyone, but many elderly are suffering in latter days because of greed and mishandling of Social Security and other programs. It's time to remove those able who will not work from assistance programs. Bring industry back to our country. Reclaim resources, repurpose and recycle everything possible. Put prisoners to work recycling instead of sitting watching tv. That could pay fines and restitution to victims. It can be done. Our forefathers worked very hard to build this great country. Time we restored it.

Regards,

Lois Chisholm

4620 Standard Wy

Fort Worth, TX 76179

Submitted on Tuesday, December 2, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because IT ALLOWS ME TO STAY HOME WITH MY LOVING FAMILY AND BUILD REAL RELATIONSHIPS WITH FAMILY AND FRIENDS AND COMMUNITY GROUPS. LIVING AT HOME WITH MY FAMILY PROVIDES ME WITH SAFETY AND LOVE. I AM THEN OF CAPACITY TO BE PART OF SOCIETY.

Regards,

Rene Aguilar

3964 Watercourse Dr

Fort Worth, TX 76109

Submitted on Friday, December 5, 2025

Dear Members of the Special Committee on Aging,

Community living matters because means freedom to live in my community instead of in a nursing home or assisted living facility it's very important because I would like to have freedom in the community instead of a facility and it would be a lot cheaper than going to a nursing home or assisted-living facility please support this bill because it's important for all people with disabilities and older adults so they can have the right to live at home and then penally with supports and it would save more from people going ending up in the emergency room or hospitals and this is important I think someone should support this because disability rights is human rights and aging people have the right to live in in place in their own homes instead of nursing homes or assisted living or any kind of institution hope you read my story thanks Linda Trongone from San Antonio Texas

Community living matters to me because

Regards,

linda TRONGONe

12926 Parton Ln

San Antonio, TX 78233

Submitted on Friday, December 5, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because: My wife and I live off of SS retirement. My son with IDD waited 18 years to get HCBS services. We had to send him to private school because Fort Worth ISD was using his special needs teacher to tutor regular kids for the TAST test while students taught my son. My son is 35 now and when he was in elementary school he was not given any type of TAST test. We spent all our savings putting my son

through school and waiting for HCBS services for the 18 years. If we did not have HCBS we could now only afford beans witha no community outings. With HCBS we have money for Ryan to participate in his community spending money, helping the economy and himself. I am old and sick and when I and his mother are gone HSBC is his only hope for any kind of life.

was not given any type of test

Regards,

Joseph Potts

20120 FM619

Elgin, TX 78621

Submitted on Sunday, December 7, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

It allowed my mother to be at home. I am a nurse's daughter, and I had the privilege of taking care of her at home.. she didn't have to wait for somebody to help her because I was always available and she did not have to deal with the neglectful care of a nursing home. People deserve to be at home or one of our arrangement they have where they can thrive and be happy.. They are not animals. With the right support there is no reason for people not to be at home if that's what they choose.

Regards,

Tina Rodriguez

3001 Avenue C

Fort Worth, TX 76105

UTAH

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have basic level human empathy for my fellow man. I know those that grew up in privilege can't comprehend the meaning of struggling and feeling for other human beings but you should know most people do

Regards,

Jonah Nelson

5882 S Nickle Way

Salt Lake City, UT 84118

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

This topic is one that really gets me kind of heated. It's tied to the economy and the fact that the cost of living is so damn high. But not just that. I suffer from mental illness. My body is starting to give out on me now also I but I have to work full time and still can't afford to support myself. The department of workforce services, however couldn't wait to take all of my benefits in fact they took them almost immediately. Yet I was told I couldn't refuse work. This is an insane way to do things in my opinion. I pay for insurance through my employer. However with the deductible as high as it is I can't afford to use it. My meditation for my mental illness alone is over 800 a month. I was denied social security back in 2015after breaking my back and a five year fight. Due to a prior drug addiction. Which blew my mind I know a lot I mean a lot of addicts who are on social security. In fact my ex husband who is an addict and has never held a job received social security because he is instutionalized and I can't get it because of a prior history. WTH. Then there is the millions of illegal immigrants who get new cars insurance monthly payments and down payment for a home. Why can't I get to the same hand up. I struggled my whole life and am now almost fifty and can't afford my rent in my tax accredited low rent apartment complex. Let alone food and everything else. I work my ass off for 15 dollars an hour. It's not right. So there you have it this is my experience with these programs. In my opinion there needs to be a

complete reform in terms of all this that for once actually helps hard working people and not just the immigrants and dregs of society.

Regards,

Tracy Oliver

Millcreek, UT 84107

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Why Community Living Matters for My Daughter and Our Family

Dear Members of Congress,

My name is Brittany Bringhurst, and I am the parent of Isabella, a 13-year-old girl with Down Syndrome and hearing loss. Isabella is currently covered by Medicaid in Utah under a Limited Waiver from DSPD. I am writing to share why programs like Medicaid Home and Community-Based Services (HCBS) are essential for families like mine.

HCBS allows Isabella to live at home, attend school, and participate in her community with dignity and independence. These services provide critical supports such as therapies, assistive technology, and respite care that make it possible for her to thrive in a family setting rather than in an institution. Without HCBS, Isabella would lose access to the resources she needs to communicate, learn, and grow. Our family would face overwhelming financial and emotional strain, and Isabella's opportunities for inclusion would disappear.

If these programs were not available, the alternative would be heartbreaking: isolation, institutional care, and a loss of the progress she has worked so hard to achieve. HCBS is not just a service—it is the foundation that allows my daughter to be part of her school, her community, and our family life.

People with disabilities deserve to live with independence, dignity, and connection. HCBS makes that possible. Please protect and strengthen these programs so that children like Isabella can continue to live and thrive in their communities.

Thank you for listening to our story and for your commitment to ensuring that all Americans have the opportunity to live full and meaningful lives.

Sincerely,

Brittany Bringhurst

Kaysville, UT

84037

Regards,

Brittany Bringhurst

581 S 350 E

Kaysville, UT 84037

Submitted on Tuesday, November 25, 2025

Dear Members of the Special Committee on Aging,

Im writing this because I have a friend who has a 80-90 % blockage in her heart and Medicaid shut her off. She has always worked and try's to find ways to help others . And she has to walk around with this blockage and can't afford to get the medical care she needs because her Insurance won't pay for it . It breaks my heart to witness people good people who work all their lives and Medicaid shuts them out . This is America . God's will be done . Not billionaires. It's becoming very dark when Money is all power . It's scary ,sad and incomprehensible what's taking place right in front of eyes. Please help the people not the dark billionaires who don't care about people at all !

Regards,

Cynthia Bingham

2246 W 2200 S

Ogden, UT 84401

VERMONT

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

so now at the age of 70 now . I seen all the years i help comfort and tried to get foods for my senior peers and Some of them suffering veterans . I can say with out the food shelf and my unpaid time to care for them. Leads me to believe if you cannot help your community and fellow man then we our lost. many of the people i cared for over the years were suffering in the communities. they wanted to stay independent but the support was very low from helps they needed live in there communities . The worsts suffer age being unable to afford medical care. So i am just going to say it is very import to try to maintain community help and support . Life matters in every community and those who had been removed to nursing homes give up and die . death rates in nursing homes and abusive action in those homes should be under investigation. At 70 yo age if i have to leave my home of 30 years then i will suffer lack of care and concern of my fellow citizen. So it matters to me and all those i get to . that are volunteer community support systems. if only the world could get that every community matters for it is the strength of our nation . it is dying. So i hope this message helps show that community matters and doing your best to help your fellow citizens is very important. Other wise we are going to see more murders and chaos. thank you. All lives matter. we need to get back on track. okay done.

Regards,

Kenneth Carpentier

293 Brookside Dr

Starksboro, VT 05487

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, like our lives depend on it at this point, after these republicans and there leader are trying to distroy what we stand for, WE THE PEOPLE DO NOT BOW DOWN TO KINGS!!!!!! for one, and we as a community must stick together!!!!!

Regards,

anna spahr

95 Center St

Rutland, VT 05701

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son is 45 years old and still lives with me. My husband and I are both in our 70's. I would really like my son to find a service supported home before we are no longer around.

Regards,

Maura Lane

PO Box 402

Waitsfield, VT 05673

VIRGINIA

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Please, do reverse all deep cuts to Medicaid, including all work requirements before 12/31/26. Thank you.

Regards,

Piotr Sliwka

9659 Manassas Dr

Manassas Park, VA 20111

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I don’t have to deal with neighbors

Regards,

Claire Terracciano

1680 Corner Rd

Burkeville, VA 23922

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to our family because of my second child.

Josh has a rare genetic disorder called Phelan-McDermid Syndrome. Josh also has been diagnosed as autistic (level 3) and has focal epilepsy. Josh requires full 1:1 support with all of his daily activities. He also is nonspeaking and currently does not have a way to communicate his wants and needs efficiently.

The services Josh receives from his Community Living Waiver allow him to thrive in our home and his school. He is also able to get out into our local community to engage in activities. Josh thrives on routines and relies on his caregivers understanding his needs. This waiver allows us to hire the caregivers who best understand and support Josh.

Without these services, Josh would be at risk for being placed in an institution. I'm a single mom and could not meet all of his needs on my own while also providing for my other children. Josh's needs are such that I cannot simply leave him with an average babysitter and no after school program exists for his needs.

When fully supported in an environment where he is comfortable and understood, Josh is what my father used to call "unfiltered joy". Josh loves life and smiles, dances, and "sings" through his days.

If Josh were to be placed in an institution, I honestly believe that who he is would begin to fade. When Josh has been forced to be in unfamiliar surroundings, he quickly can get frustrated. He engages in self-injurious behavior (he harms himself) or he can lash out at others. He also tries to escape unfamiliar places.

Please continue to support the Community Based Services. My son Josh, and others like him, deserve to live where they can be comfortable, cared for, and where they can thrive.

Regards,

Lisa Giamette

12004 Alum Springs Rd

Culpeper, VA 22701

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am currently living with three disabilities, HS, Fibromyalgia and spinal stenosis. I have always worked in spite of my disabilities until last year when I was diagnosed with Stage IV Hodgkin's Lymphoma. I under went 6 months of chemo therapy which greatly impacted my strength and cognitive abilities. My job at the time was very physically and mentally demanding and they would not keep me on light duty for the 6 months I needed to recover. I lost my home, my job, my insurance all in one go. I had to move in with a family member, but due to the horrible private Healthcare system in America, I could not get medical coverage. To top it all off my other disabilities were aggravated by the chemo, so my recovery from cancer has been even slower. My blood must be monitored for 6 years because of my cancer and as soon as I lost my health insurance the cancer center where I was treated, who charged and was paid over 2 million dollars for my treatment, canceled all future appointments. I applied for financial aid through their in house program and was denied. I had no recourse left but to apply for Medicaid for the first time in my life. I have always prided myself for working and providing myself, my children and my spouse with medical health insurance, so it was a humbling experience to have to even ask for assistance in this way. However, having a chest port that needs to be flushed monthly so I do not develop blood clots, as well as continued monitoring of my blood for return of the cancer left me no choice. I have recently learned my cancer has returned after only 6 months of remission. I live in fear that Medicaid will be ripped away from me before treatment can be completed and I will be forced to just accept my own death at just 56 years of age. The stress of that adds to the burden of my other disabilities as it causes flairs making me weaker and harder to move forward with my life. I live every day in fear that a system I have worked and paid into will be ripped away by people who have never had to struggle.

Regards,

Susan Dixon

839 Little Bay Ave

Norfolk, VA 23503

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because,

How do programs like Medicaid HCBS impact your life? The programs have helped me thru very difficult times dealing with the brain cancer I have. It has and continues to allow me to be able to reach out to others even though I may be isolated due to my illness and know that I have a safe place to talk about any issue I may have.

What would happen if you or someone you know didn't have them? I would feel more isolated and the chance to receive any help I need would be gone. When you have to face dying and death like I have had to so far any amount of encouragement is a blessing from Heaven for sure.

Regards,

Terry Scott

904 Hendrick St

Culpeper, VA 22701

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because as someone with mild IDD I can't live without it like everyone with disability that's living on their benefits

Regards,

Nick Zweerink

5322 Markel Rd

Richmond, VA 23230

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

My adult daughter has Down syndrome and autism, as well as an anxiety disorder with OCD, and leans heavily on the support provided by her Medicaid HCBS. Without it, her quality of life would evaporate, and her connection to her community would disappear. She

is completely incapable of caring for herself. With the help currently in place, she is immensely happier and more functional. Thank you for your time.

Regards,

Joseph Anthony

3977 Oak Hill Rd

Buckingham, VA 23921

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, I want to stay in my home. My sister is my paid caregiver. Without the Medicaid program. I would not be able to stay with my sister in our home. Because she has to make a living also. And it keeps me out of a nursing home. Where I have to worry about my health and safety. Thank you!

Regards,

Debra Chappell

1910 Atkins Mill Rd

Wytheville, VA 24382

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a

44 year old son with intellectual disability from birth. He has always been with me but I'm 77 and

dread leaving him. He has SSDI and works but to do that he has a job coach from the city and I drive him to work and back and if either of those things fell out it would be very bad for him.

Regards,

donna payne

4604 Bunker Hill Ln

Virginia Beach, VA 23462

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because 2 of my students in special education lost their mom when they were teenagers back in 2000. They both have significant disabilities and they literally had no where to go and no family member willing to take them. As a transition coordinator, I was able to help both of them get the medicaid waiver and move into sponsored residential homes in our area. Now, as their guardian, I can depend on the community service board and local agencies to manage and maintain their services. They both love living with their respective families. They both participate in a wide range of community activities. Without medicaid waiver and the excellent support systems developed in Virginia, they would be homeless or institutionalized. Community based services saved their lives!

Regards,

Elliott Johnna

1108 Kentwood Dr

Blacksburg, VA 24060

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it's how many of us survive. Medicaid HCBS helps me get the assistance I need for mental health, skill building and primary care. If I didn't have them, I'm not sure what I would do because it would be difficult functioning without them. I've learned essential skills to help me be a better person, received medication management, counseling, medical and dietary advice. I am grateful. Happy holidays!

Regards,

Norman Faria

1104 Deaton Rd SE

998

Roanoke, VA 24014

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living is essential for our 18-year-old daughter Eliza because it supports the independence and adult life she has worked so hard to achieve. Eliza has Down syndrome and worked hard to graduate with a standard diploma from the same public high school that her big sisters attended. Throughout her school years, she thrived in inclusive environments that valued her abilities and empowered her voice. Now, as a young adult, she deserves the same opportunity to continue that growth in real-world settings where she can build relationships, develop skills, and pursue her dreams.

Our daughter is already deeply engaged in her community. She performs with the Arts for All theatre program, where she has built confidence, friendships, and a true sense of belonging. She proudly participates in Special Olympics sports, where she enjoys being part of a competitive, supportive community. Every week, she volunteers at both the local hospital and the animal shelter, giving her time and energy to help others—work that brings her incredible pride and purpose. On top of all of this, she is taking college courses at our local community college, demonstrating her commitment to continued learning and her readiness for greater independence.

These experiences aren't just activities—they are evidence of the full, vibrant life she is already building. Community living would allow her to take the next steps in that journey. It gives her the chance to make age-appropriate choices, manage responsibilities, and deepen her independence with the right supports in place. It also enables her to grow socially while staying connected to the programs and people who enrich her life.

Most importantly, Eliza wants to be independent. She desires a life where she can contribute, connect, and flourish just like any other young adult. Community living honors that desire by providing both safety and freedom. It creates the bridge from high school to adulthood in a way that aligns with her goals, reflects her potential, and respects her right to a meaningful life.

For her—and for our family—community living is not only appropriate, but also necessary. It allows her to continue the purposeful, engaged, and independent life she is already working to build, and it gives her the inclusive future she deserves.

Please continue to support programs like Medicaid HCBS for Eliza, and other young adults like her.

Regards,

Pam Schoppert

704 Brigadier Ct SE

Leesburg, VA 20175

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because part of the beauty of life is meeting people from all walks of life. There is so much to learn from people who are fundamentally different from you, and I think it's amazing. The elderly and disabled people deserve to have safe housing that can support them and their needs. Knowing that those who are near and dear to us are being well taken care of can give us peace of mind, especially as our family members advance in age. Not everyone has the financial or mental capacity to provide for family members with increased medical needs, so programs like Medicaid HCBS are crucial. Please support programs like this.

Regards,

Kiana Mitchell

8869 Pennock Ct

Linton Hall, VA 20136

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because the GOP is trying to make America into Nazi Germany!

Regards,

Steven Urquhart

1801 Warrington Rd SW

Roanoke, VA 24015

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it is the essence of humanity.

Regards,

Teresa Bohan

3409 Martha Custis Dr

Alexandria, VA 22302

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because without community we have nothing.

Regards,

James Mather

9204 Ox Rd

Lorton, VA 22079

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because because my intellectually disabled son is able to develop social skills outside of my home. Although he is able to work in a special needs workplace, he could never afford rent without rental assistance that he receives. I just wish the annual application process was not so overwhelmingly burdensome. One sole person in the county handles about 150 cases all within a few weeks of the application window. As I age, I worry about who will help him with this when I no longer can.

Regards,

Esther Baldivia

7209

VA 22307

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it’s very important for people with disabilities to remain independent.

Regards,

Cynthia Leonard

1900 Lauderdale Dr

Richmond, VA 23238

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Programs like Medicaid HCBS allow adults with intellectual disabilities to truly be part of the community. I've seen how important this is as a volunteer at L'Arche GWDC's home for life on Highland Street in Arlington County.

Four "core members" enjoy life as family, buildling lifelong relationships within the home, in the neighborhood and across the community. Their interests range from softball, gym workouts, and swimming to community theatre, reading, gardening, and watching Star Trek reruns.

My husband, who has also been a L'Arche volunteer, had an uncle who had intellectual disabilities. The family had no option except to warehouse him in an institution since no one was available to help him navigate the community. Options like the L'Arche homes for life were not available then.

Please ensure that adults with intellectual disabilities continue to have access to a fulfilling and empowering living environment -- a setting made possible in part through the Medicaid program.

Regards,

Sandra Cleva

513 W Broad St

Falls Church, VA 22046

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

HCBS Medicaid funding makes it possible for people with disabilities like me to not only live in comunities but to thrive. Without it my future would be very uncertain. You have a great opportunity to make a very positive impact on the lives of millions of Americans with disabilities.

Regards,

Heather Heflin

6304 Belleair Rd

Burke, VA 22015

Submitted on Sunday, November 23, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because our daughter spends money in our community and

The people helping her with her transactions recognize and acknowledge her importance.

She feels that she is included, and part of her community. She can also help the community.

By donating items to the Salvation Army so others may benefit . We teach her, you may need help, but we can also help others in the

Community. Anything is appreciated. Please hear her voice-she is non verbal. Thank you.

Regards,

Laurie Carrero

3001 Kathleen Way

Williamsburg, VA 23188

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have an adult son who was born with a genetic anomaly. He will never been able to live independently. HCBS are so important for people like him in many ways. Once people with disabilities age out of the school system there are very few programs available, HCBS fills that gap. What it means for him is a community, friends, a sense of purpose, a place where he can continue to learn and grow with his peers. As his parent, I know I won't always be here to care for him or manage his care, HCBS is the safety net for him. If my son did not have his day program there would be nowhere for him to go, it just doesn't exist outside of the system. As he ages and I age these programs become even more critical not just for his quality of life but his LIFE. It cannot be overstated how important these programs are for my son and others who rely on them.

Regards,

Adriana Sturdevant

4700 Catharpin Rd

Gainesville, VA 20155

Submitted on Wednesday, November 26, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I can talk to my friend and learn of news this that are hapining

Regards,

Phyllis Hagmaier

2899 Lake Powell Rd

Williamsburg, VA 23185

Submitted on Sunday, November 30, 2025

1004

Dear Members of the Special Committee on Aging,

Community living matters to me because due to a divorce my son no longer has financial support from his father. I work 2 jobs just to help him with groceries living paycheck to paycheck in Virginia. In 2025 , 5 years post divorce , due to his disability support with his Medicaid waiver, SSDI and SRAP in Loudoun County, was granted a housing voucher with in home support. The disability community has been severely impacted by COVID shutdown and now the most recent government shutdown. I urge our government to find funding to support the needs of the disabled community all across our communities.

Regards,

Pamela Treer

44872 Rivermont Ter Apt 205

Ashburn, VA 20147

Submitted on Wednesday, December 3, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have two autistic, 17–year-olds, with relatively low support needs who will not be able to get jobs and live lives where they will be able to contribute to society without community living.

My biggest concern is where and how they will live after we pass away and before, when we become too old to care for them.

The supports they need are not available privately. No amount of private money can buy them.

Will my disabled adult children become homeless, all for the lack of a job coach, or someone check in on them or to remind them to do what they need to do to take care of themselves?

Is the only way to keep a roof over their head going to be institutionalizing them?

That’s what we did to people 60 years ago.

The Supreme Court declared that they have a right to live in the community like everyone else.

Beyond the moral imperative, it is less expensive to house And support people in the community than it is to institutionalize them.

I can’t sleep at night, worrying about what will happen To my disabled adult children after I am no longer able to care for them, if these supports do not exist.

Thank you.

Regards,

Kathleen Walsh

2201 Kilt Ct

Alexandria, VA 22308

Submitted on Friday, December 5, 2025

Dear Members of the Special Committee on Aging,

As an advocate and care provider, I see firsthand every single day how people thrive when given choices in their lives. Little is more impactful than a person knowing their desires, dreams and needs are respected. The value of HCBS in our community can't be underestimated and must be protected. I can not imagine the harm our most vulnerable and deserving citizens if the funding provided through Medicaid programs that support HCBS living is reduced.

Respectfully,

Gayle Dillon, M.Ed

Group Home Provider

Community Program Director

Former Publix School Educator

Lifelong Advocate

Regards,

Gayle Dillon

15094 Hawks Climb Ln

Montpelier, VA 23192

Submitted on Friday, December 5, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my husband and I are caregivers for our adult son with profound autism. He needs 24/7 care. There are many families like ours who rely on HCBS.

Regards,

Greta Selden

10121 Hollythorne Ln

Mechanicsville, VA 23116

WASHINGTON

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because

Hello, I have an adult son with Autism.

He has Diabetes and high cholesterol.

He needs Medicare for his medication and doctor appointments and bloodwork.!

It is of upmost importance he receives the medical care he has been receiving.!

Please Do Not Take this life saving coverage away!

Thank You for taking your time reading this letter!

Sincerely, his Mom, Cathy

Regards,

Cathy Hickman

Ellensburg, WA 98926

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son Ian has been receiving community services since he was 15yo, he is currently 37. During Covid these services were limited and I noticed that he wasn't eating or bathing on a regular schedule and he was upset and angry a lot. I am his primary caregiver and he relies on these services for support to be able to survive.

Regards,

Casey Forsyth

Olympia, WA 98502

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because our 40 yr old daughter lives with Autism. She needs care and she needs Medicare to fill in the gaps to pay those costs.

Regards,

Walter Abplanalp

277 Tucker Rd

Ethel, WA 98542

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because recently widowed medicaid was there for me during a health crisis.

Regards,

Leon Robert

5815 6th Ave NW

Seattle, WA 98107

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me becauseour daughter also has Medicaid and needs it to fill in the gaps

Regards,

Walter Abplanalp

277 Tucker Rd

Ethel, WA 98542

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have autism and what if I can't find a job prior to running out of money?

Regards,

Matthew McDonald

12508 Lake City Way NE

Seattle, WA 98125

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows people of all ages to access their community. It allows for essential therapy services, health and wellness, disability awareness for people needing home, as well as educational and transportation services.

Regards,

Meghann Delaplaine

28606 16th Ave S

Federal Way, WA 98003

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

My husband and I adopted our developmentally disabled daughter from the state of Washington when she was a baby. During her childhood, we asked for little help from the state, but now, as an adult, she relies on Medicaid home and community based services to fund a caregiver and an employment coach, as well as medical coverage, so that she can be as independent and productive as possible in her community. If she was without these services, she would be very alone when we die. It is the responsibility of the government to care for all of its citizens and to provide the means for life, liberty, and the pursuit of happiness. Developmentally disabled persons are citizens. Please provide for their needs.

Regards,

Patricia Leinweber

19542 Echo Lake Pl N

Shoreline, WA 98133

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

While I don't receive Medicaid, I know those who do and wouldn't have medical care without it. Their health and quality of life would be greatly at risk without Medicaid. Their health cost of healthcare must be reduced significantly so that everyone can afford coverage!

Regards,

Corrine Anderson-Ketchmark

506 S 222nd St

Des Moines, WA 98198

Submitted on Thursday, November 20, 2025

1010

Dear Members of the Special Committee on Aging,

Community living matters to me because I have an adult daughter who has autism and she depends on those services. She has a job, works 32 hours/week, lives in a supported home and receives job support services. She is an active member of her community and pays into social security. She doesn't get a large amount of support, but if that support goes away, her chances of becoming homeless will go up drastically. Her dad and I sought supported living services for her this year because we are 70 and desperately want to know that after we're gone she will be in a safe sustainable situation. Please don't jeopardize her long term life plan!

Regards,

Jill Gilliom

1900 Emerald St

Milton, WA 98354

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

I am a disabled 68 year old woman. If it wasn't for home care I would be stuck in an assisted living situation. A place where I can't have my dogs or garden.

My caregivers help me with many things, cooking, cleaning, bathing, dressing, Dr appointments and shopping.

Some days I do pretty good being able to dress myself, bathing, etc, but those days are few.

I live with chronic excruciating pain almost daily. I've now been bed ridden for two weeks in hopes that my lower left back n leg pain get better.

This home care and assisted living is mostly the only social interaction we have.

No one ever visits me unless I call my 1 friend for help.

We need hygiene supplies, laundry and other cleaning products that our insurance doesn't cover... We've worked our entire lives just to have our benefits consistently cut every year. It doesn't even ad up to the actual cost of living.

Thank you for taking the time to read this.

Regards,

Cathy Petheram

7016 E 2nd Ave

Spokane Valley, WA 99212

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

If Medicaid was taken away, I'd have 5 blood relatives on the streets, and several would die due to PTSD and mental health!

Regards,

Connie Grant

950 Vineland Dr

Clarkston, WA 99403

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my youngest brother, who is sixty-six and developmental disabled, has been living in community for twenty years. I am his guardian and am indebted to the people who care for him. Without 24/7 care he would not be able to function. With it he lives with three roommates who are also disabled. Each of them works outside the home, and enjoy social activities, but their interactions as friends is what gives the most satisfaction.

At eighty I am unable to care for my brother and frankly do not know how long I may be present in his life, but I am grateful that I know he will be secure in the future.

Please do everything necessary to support those who are aging or disabled.

Sincerely

Rowena M Donelson

Regards,

Rowena Donelson

7637 Woodland Rd

Ferndale, WA 98248

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I care

Regards,

Ibrahim Hafid

5612 186th Pl SW

Lynnwood, WA 98037

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I care

Regards,

Ibrahim Hafid

5612 186th Pl SW

Lynnwood, WA 98037

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I live on SS and rely on Medicare and medicaid for health care. Food stamps and the local Community Action Food Bank help me keep food on the table and my house warm and utilities on. I'm 81 years old. Three decades ago I was a CNA and worked as a Skills Trainer for developmentally disabled adults in Salem OR. The job opened my eyes to the true joy of being alive with or without a perfect mind and body.

We must as humane creatures care for and sustain all living beings without exception otherwise our own lives are without much value.

Regards,

allen haydon

PO Box 803

Tekoa, WA 99033

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because without that I would not be able to participate in activities outside of my home I would be housebound. I struggle with depression. My only connection to the outside world would be through social media or FaceTime. this would be a severe impact in my life and not allow me the quality of life that other people could and do experience. Equity is a strong word these days removing these funds from this population is not equatable not fair and these folks deserve to live a life like any other person. we work and make contributions to the community on many different level's so we should also be able to receive the benefits of being in Community because we are part of that community. We work we play we interact with our community on many different levels please consider this plea and do not remove these services.

Regards,

Tami Slack

3328 McAlpine Rd

Bellingham, WA 98225

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

I received a diagnosis of MS in 1974 but continued living my life as normally as possible. Then a friend suggested that I check into the local social services office where I was given information about doctors who turned me on to Medicare and Medicaid. Currently I'm learning about HCBS, however this may answer that: I now abide in an excellent nursing

home that provides my medical care. I suspect most if not all residents here fall into the same category as me: dependent on Medicare/Medicaid and praying that it won't be disappeared.

Regards,

Waldemar Itrich

Cashmere, WA 98815

Submitted on Monday, November 24, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I am a widow age 62. My husband of 36 years died in 2021. He and I owned a small auto repair shop for 20 years and our biggest mistake was never preparing for our later years. We chose not to pay into Social Security because everyone said it would not exist when we needed it. We agreed to be responsible and save the money ourselves. Never happened. So now I am 62, I haven't worked since too many surgeries and too many sick days made me lose my job. On top of that I am going blind due to retinal deterioration. If it weren't for the support of my community and my children I would literally be living on the streets begging for my survival. Thanks to my community I can come and go as needed because of Metro and Hopelink. When my SNAP benefits were threatened last month I checked into alternatives and found that there are many sources for foodbanks. My community is prepared. I just pray that things don't get any worse before they get better.

Regards,

Laura Waite

Redmond, WA 98053

Submitted on Tuesday, November 25, 2025

Dear Members of the Special Committee on Aging,

I worked as a Medicaid personal care assistant and respite care provider for many years. My young, disabled clients needed help with all their ADLs and IADLs. With that help, they were able to grow up and go to college or get jobs or move into supported living. And my life

has been greatly enriched by getting to know them and helping them grow up into adults involved in their communities.

I was also a special education teacher until my own disabling health condition made it impossible to continue classroom teaching. Most of my former students will never live independently due to their developmental disabilities. In-home support enables them to live, and to have lives worth living, interacting with the world on their own terms, and being a boon to everyone lucky enough to know them.

Now I am medically disabled and my care is provided by my elderly parent. Obviously this is not a long term solution. The day will come when my parent is unable to provide my care, when we will both require caregivers. And when that day comes, I need to have access to the same supports I gave my clients and students. I have a life worth living, and I enrich the lives of those around me. I deserve to live with dignity, in a home of my choosing, and to have my basic needs met too.

Regards,

Jessica Johnson

2224 White Fir Pl

Freeland, WA 98249

Submitted on Wednesday, November 26, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it is so necessary to not only survive, but to thrive as a community. There is a city ordinance that states, if it gets colder than 46 degrees fahrenheit, you need to bring your pets in or you will be fined. It was 39 degrees fahrenheit last night and pouring rain. It is still pouring rain. There are people outside, as there are no shelters available, no spaces indoors in the day time either! Where is the humanity in government? A priest that I know performs memorials for the homeless. He has performed 981 this season, so far! Medicare and Medicaid are services that could have helped these folks. We are all so close to losing housing because of medical bills. That is what is happening all over America. Kiddos that were in foster care and have turned 18, are homeless. They have no money and no one is getting paid to house them any longer. They need to take care of themselves. Dentists and doctors are paid by Medicaid. Abused women and children flee beatings only to die in the bitter cold, hungry and cold. What God would want this for his people? Fascism sucks. Tax the Rich for the love of God. Israel has

free college for all, free medical for all and we are sending them money so they can blowup Palestinians? How stupid and evil is America? We are the only country that has welfare that only helps the wealthy. Maga organization is a terrorist organization. We are all to be victims of the morally bankrupt rich. There is nothing radical about moral clarity.

Regards,

Rene Cournoyer

3115 S 19th St

Tacoma, WA 98405

Submitted on Tuesday, December 2, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my daughter's life is highly impacted by autism. She needs 24-hour care and supervision for her safety and to thrive.

She pays her own rent to share a home with 4 other clients, and is supported by loving and devoted care workers who are also paid by Medicaid.

Without Medicaid-paid community-based services, my daughter could not enjoy her home, and would not be contributing to her community as you and I do by shopping, paying rent and utilities and paying taxes in her home town.

Repeal cuts to Medicaid. SAVE HOME AND COMMUNITY BASED SERVICES.

Regards,

Teri McKeehan

127 E Intercity Ave Ste C

Everett, WA 98208

Submitted on Thursday, December 4, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows me to be included in the community and keeps me from being isolated. Services provided by a Medicaid Home and Community

based service waiver help provide services that allow me to live my best life. These services also provide respite and personal care for me as well.

If there are cuts to Medicaid Home and Community based services, I will be isolated at home and my parents who are my primary caregivers will have to take most of the burden. We need more funding for these waivers instead of cuts. Medicaid is more than health insurance for disabled people like myself, they are a life line and helps me be more included in the community.

Regards,

Christine Motokane

21 Lighthouse View Dr

Sequim, WA 98382

Submitted on Thursday, December 4, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it allows me and my husband, both retirees, to still spend quality time with our 32-year-old daughter who has significant IDD while she lives in a home with professional caregivers and constant supervision. She continues to work and recreate in her community with her friends. It is a vital service for her well being and continuing care.

Regards,

Rebecca Bisbee

5435 116th Pl SE

Bellevue, WA 98006

WEST VIRGINIA

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, my Father in law is elderly and disabled. Without Medicare he wouldn't have great Healthcare, he wouldn't be able to age in place!

I couldn't imagine having to put him onto a nursing home,he grew up in the country, lived his entire life on a farm, now then he became disabled , he was still able to stay on his farm because of medicaid, his medical needs were met, and his son helped him, along with many family members.

Now he is elderly, sold his farm, and lives in a trailer near us, his health care is taken care of and since he doesn't have to pay for insurance his social security goes towards his groceries and any other needs he has....please continue disability services!

Regards,

Jean Mullins

1769 Big Pigeon Rd

Pigeon, WV 25164

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have been living in a tent. 64 with painful p.v.. when it got in the 20's it was rough folks figured I will freeze to death... I need help.

Regards,

william mcyoung

13281 Jerrys Run Rd

Apple Grove, WV 25502

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

The Honorable Members of the United States Congress

Washington, D.C.

Re: The Critical Importance of Medicaid Home and Community-Based Services (HCBS) and Waiver Programs

Dear Members of Congress,

I am writing to urge you to continue protecting and strengthening Medicaid Home and Community-Based Services (HCBS) and Medicaid waiver programs. These programs are not only life-changing for individuals with disabilities and their families—they are also fiscally responsible, humane, and essential to ensuring safety, independence, and quality of life.

My daughter is one of the many Americans whose life has been transformed by HCBS. When she first began receiving home-based waiver services, she was completely nonverbal. Through access to speech therapy, occupational therapy, physical therapy, and communication-technology supports—services our family could never have afforded without Medicaid—she has made tremendous progress. She has learned to communicate using a device, she self-teaches in multiple languages, she swims, rides a bicycle, and expresses her love for music. These milestones were only possible because she is able to receive consistent, qualified care in the safety and comfort of her home.

As her full-time caregiver, I am unable to work. Her needs require 24/7 care, supervision, and support. Without Medicaid waiver services, my daughter would have no option but to enter an assisted living or institutional care facility. Such placement would cost the state millions of dollars over her lifetime—far more than the cost of providing home-based services. HCBS allows families like mine to provide safe, loving, personalized care at a fraction of what institutional care requires. It is both the compassionate and financially prudent approach.

In addition to the financial benefits, HCBS protects disabled individuals from the significant risks associated with institutional settings. Reports of abuse and neglect in care facilities across the country are well-documented. My daughter is nonverbal and would not be able to report mistreatment. In a facility, she could easily lose the skills and progress she has worked so hard to gain—progress she would likely never regain. Her safety, well-being, and development depend on her ability to remain at home with people who love her.

Medicaid waiver programs promote independence, dignity, and meaningful community involvement. They give disabled individuals a chance to thrive, learn, grow, and one day

potentially live more independent lives. Eliminating or weakening these programs would not only endanger countless families, but would also lead to far higher long-term costs for states and the federal government.

I am asking you—on behalf of my daughter and thousands of families like mine—to protect and expand Medicaid home-based services. These programs are not optional; they are vital lifelines. They keep vulnerable individuals safe, support family-based caregiving, reduce institutional reliance, and ensure that people with disabilities can live full and meaningful lives in their own communities.

Please do not eliminate or reduce funding for Medicaid HCBS or waiver programs. Our family, and so many others across this country, depend on these essential services.

Thank you for your time, your compassion, and your commitment to supporting families and individuals with disabilities.

Sincerely,

Tiffany Love

Re/: my daughter, Audrey "Bella" Love

Regards,

Tiffany Love

WV-61

WV 25840

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

I am a person with disabilities and have been assisted my DRS services in obtaining my RN degree. My pinning is in a few weeks and this would never have been possible without programs like these. Now my husband and I will not have to spend our entire existence living off these programs and can actually LIVE instead of merely survive. That's what generally what these things allow most people to do ...survive....so without them, their survival rate would decline, not to mention their quality of life! Please do not take these programs away. I am proof that they can be utilized to improve your life permanently and should continue to be available to those who can follow the rules and lean instead of depend. Thank you! God Bless!

Regards,

Brandi Gunnoe

68 Leftwich Ave

Madison, WV 25130

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because human beings deserve resp

Regards,

PAMELA JOHNSON

349 Keystone Dr

Charleston, WV 25311

Submitted on Saturday, November 22, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I can live with my mother and we help each other. We share cooking, house cleaning, yard work, and animal care. My anxiety and depression are less having her around and helping me face my daily challenges. I'm also Autistic and she helps me by managing my Medicaid, SSI and food stamps. She is also retired and my rent payments help both of us have a home to live in.

Regards,

Ryan McKinley

177 Meadowlark Ln

Shepherdstown, WV 25443

WISCONSIN

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because the disabled U.S. military veterans I serve at my American Legion Post 21 in Kenosha, Wisconsin, deserve care and continue to give back to the community as they are cared for.

Regards,

KAREN OBRIEN

Kenosha, WI 53142

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I'm a disabled veteran. Currently an employee, Bonnie, here at Howard Village (a Sinceri senior apartment complex) is protesting the living conditions of veterans living here. The manager, Matt Fischer, conducts himself as if he were a king. In my case, I was in the hospital for 14 days. According to my lease, after 7 days I was entitled to a refund for meals I missed. Mr. Fischer denied my refund request until a Sinceri corporate executive intervened. I was finally given the refund.

Regards,

John Hien

2500 E Howard Ave

St Francis, WI 53235

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because it helps many people who without would be unable to get the help and care they need.

Regards,

Chris Chatham

1023 Main St

Eau Claire, WI 54701

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

For myself, and millions of others with disabilities, living in our communities is everything!! If I am not able to live in my community that would mean giving up all of the activities I'm involved in; most of which are rooted in disability advocacy. Being able to live in my community gives me friends, freedom and access to local events. Just today I was able to attend a meeting at my local senior center to talk about fundraising opportunities for an inclusive park being built in my town. I also was able to be part of a promotional video for the park. Programs like Medicaid HCBS have been vital in helping me get accessible housing at an apartment complex in my town. Before moving out to my own place I was restricted in where I could go on my own and my interactions were largely through email/social media. There are still accessibility issues with a large portion of buildings in my area, but now living near downtown I am able to explore more. Please don't take away my freedom and right to be an active member of my community. Thank you!

Regards,

Kristi Scheunemann

201 S Water St

Watertown, WI 53094

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Hello, my name is Jordan. I have some issues typing so if you guys could get in touch with me, but I have a story that I would like to share, but I wanna make sure I capture everything that you would like me to.

Thank you

Regards,

Jordan Anderson

5203 Maple Rd

Auburndale, WI 54412

Submitted on Thursday, November 20, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, I was able to live on my own, in the city, then i had more seizures. I moved back in with my parents I am now looking for a new place, if it wasn't for medicaid i would not be able to afford my medication to keep my epilepsy under control, I also have more medications. Medicaid HBCS,will help me get and stay living independently.

Regards,

Tanya Roberts

434 Forest View Rd

Oshkosh, WI 54904

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because we must all work together and learn togeather and make things better for all!

Regards,

Roger Schmidt

914 Royster Oaks Dr Apt 109

Madison, WI 53714

Submitted on Friday, November 21, 2025

1025

Dear Members of the Special Committee on Aging,

Community living matters to me because my husband and I live on Medicare as does my special needs niece and nephew!

Regards,

Diana Lewis

36077 Ravinia Park Blvd

Oconomowoc, WI 53066

Submitted on Wednesday, December 3, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because I have a 45 year old daughter who has autism, intellectual disability and physical disability. Throughout her 21 years of schooling, her rights were continually violated and our family had to hire tutors, attorney's, file complaints with the department of education, and move three times trying to get her better services. Our income was severely impacted due to those in the public school system not following the federal and state laws. After all of her hard work, and our family's sacrifices, she owns a condo on the west side of Madison and continues to work two part time jobs that she's held for over 25 years. She lives far below the poverty line, relying on funds from my husband and me, and relying on Medicaid to pay her support team of workers who provide 55 hours per week. That support team helps drive her to/from her 2 jobs, wash her hair, plan and prepare her meals, balance her very tight budget, get her doctor and therapy appointments, and take her to the fitness center so she can remain strong enough to tolerate being on her feet at work. I volunteer around 15 hours per week recruiting, training and supervising her 5 staff and I fill in when staff can't cover a shift. I have no idea who will provide that much free support and extra funds when I die. I'm 74 now, and the stress has taken a great toll on my memory and physical functioning.

If you make any cut to Medicaid, no matter how small, we will likely lose staff because they are already grossly underpaid. I don't have the energy or skills to fill in or any more time than I'm already providing. Megan will likely need to quit her two jobs, give up her condo, and move in with me, in a neighboring city. You will be destroying a very fragile system of support that is already based upon too low of wages to recruit and keep support staff for more than a few months before they quit and I need to try recruiting again. The research is there; you and all of us know that community living is far less expensive than institutional

living (1/10th the cost). So, I imagine that if you cut medicaid you are actually aiming to kill the millions of people with disabilities who have aging parents who can't help them OR who have no parents alive and able to take over. You will be forcing people with disabilities to live on the streets, where the current president will round them up and put them in holding centers with no health care and little food and water. You will be murderers. We see you. We see your goals. Our family and my daughter have been paying taxes our entire lives. We aren't cheaters, like the Republicans in Congress who have been making millions off the stock market ups and downs, designed by the president's game with tariffs. We know what you are doing. If you cut one dollar of Medicaid, you will be murdering your own constituents. Shame on you for even considering this, along with SNAP cuts, along with destruction of USAID, along with cuts to OSEP, along a tax system that allows billionaires to pay NOTHING. If you kill more vulnerable people, I pray that you will will be replaced, then tried and convicted, then spend your life in prison, then pay your dues when you are judged by God.

Regards,

Laurine Lusk

7127 N Shore Dr

Belleville, WI 53508

Submitted on Thursday, December 4, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my son has Down Syndrome. While he is young now, every support he has had to make him more independent and more able to succeed like the other kids in his class has made an incredible impact on his development and his happiness. I hope when he is older there will still be programs that allow him to participate in his community, attend school and work, and support him. It makes all the world to people like my son and the exhausted family members who do everything we can. But we can't do it without support through HCBS and Medicaid. Thank you for reading this.

Regards,

Christoher Rates

PO Box 4

Winnebago, WI 54985

WYOMING

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because my community is thriving and full of good people.

Regards,

Sue Krause

1822 E 18th St

Cheyenne, WY 82001

Submitted on Friday, November 21, 2025

Dear Members of the Special Committee on Aging,

Community living matters to me because, the elderly and disabled people like me that can't work and only have a small social security to live on deserve everything possible I can get to survive and with the cost of living these days every little thing helps. Don't understand why the elderly and disabled keep losing everything like their benefits and health insurance and they pay more for things like healthcare.

Regards,

Julie Bird

2606 Monroe Ct

Riverton, WY 82501

THE SCAN FOUNDATION

Statement for the Record
Senate Committee on Aging Hearing "Aging in Place: The Impact of Community during the Holidays"
December 3, 2025

The Honorable Rick Scott
Chairman
United States Senate Special Committee on Aging
G16 Dirksen Senate Office Building
Washington, DC 20510

The Honorable Kirsten Gillibrand
Ranking Member
United States Senate Special Committee on Aging
G16 Dirksen Senate Office Building
Washington, DC 20510

Dear Chairman Scott and Ranking Member Gillibrand,

The SCAN Foundation appreciates the opportunity to submit this statement for the record in relation to the Committee's December 3, 2025 hearing, "Aging in Place: The Impact of Community during the Holidays."

The SCAN Foundation is a California and nationally-focused, non-partisan foundation that works towards a society where all of us can age well with purpose. The SCAN Foundation integrates policy and programmatic grantmaking with mission-aligned impact investing to drive near-term solutions and long-term, systems level reforms. We pursue this vision by igniting bold and equitable changes in how older adults age in both home and community.

We appreciate the Committee's interest in elevating the importance of programs that help older adults and people with disabilities remain in their own homes and communities. This starts with ensuring that these individuals can access the long-term services and supports (LTSS) they need, especially those offered through the Older Americans Act (OAA) and through Medicaid's home and community-based services (HCBS) program. Medicaid HCBS is the largest payer of home care in the country and makes it possible for millions of low-income Americans to receive the kind of help with daily activities that keeps them from having to move to an institutional setting, which can reduce health care system costs while improving individual care experiences. Indeed, we know that most older adults want to age in their own homes and communities, and we need more investments and policy support to ensure those preferences can be honored now and, in the future, when demand for long term care in the home will rise exponentially.

And while it is critical to continue to bolster the Medicaid HCBS and OAA systems and workforce, policy solutions to support the home care needs of middle-income Americans and their families, those in the so-called "Forgotten Middle", are also desperately needed. This group, which will grow to 16 million people by 2033, is ineligible for Medicaid, yet still unable to afford the health, home care, and housing services that can help them remain in their own communities as they age. There are virtually no public programs to assist these older adults and

their families, and with the median annual cost of private pay home care hitting nearly $78,000 in 2024, most cannot afford paid help, and have to rely on over-burdened family caregivers, increasing numbers of whom are reducing their own working hours or dropping out of the workforce altogether to help take care of their loved ones.

The country needs bold new initiatives in order to address the exploding demand for home- and community-based care of all kinds. Fortunately, there is bipartisan support for a host of public policies to help pay for the costs of long-term care and caregiving, many of which would involve an expanded role for the federal government. Likewise, policymakers do not need to "start from scratch" when it comes to designing the details of specific proposals; over the last 40 years, there have been many ideas put forward, by Congress, researchers, advocates, and other LTSS stakeholders.

By recognizing the urgent need for LTSS and HCBS solutions, committing to act, and using the lived experiences and feedback of actual users of long-term care to guide its work, Congress can help millions of older adults and people with disabilities stay safe, secure, and supported in their homes and communities.

There is a Rich History of LTSS Policy Solution Development

Data and the lived experience of millions of families across the country indicate that people struggle to pay for and coordinate the LTSS that supports daily living activities like bathing, eating, and dressing. These services are not covered by traditional Medicare, even though many Americans incorrectly assume they are. Medicaid remains the country's largest financing source for HCBS, and six out of ten Americans plan to rely on Medicaid to meet their long-term care needs in the future. But Medicaid HCBS is chronically underfunded, with estimates of nearly 600,000 individuals on waitlists for the services in 2025. At the same time, recent federal legislative changes to Medicaid could strain the HCBS system even further, as states grapple with hard decisions about whether and how to cut their HCBS programs to make up for financing shortfalls. This policy shift—combined with an aging population, long-term care workforce shortages, fewer available family caregivers, and a growing retirement crisis in which most people lack adequate savings for future care—has created a significant gap in America's care delivery system. Addressing this gap is essential to ensuring that older adults and family caregivers can access the support they need.

Luckily, Congress has, at various times, considered legislation to make LTSS more accessible and affordable. Similarly, researchers and aging and disability advocates have developed policy concepts to further address the need. The SCAN Foundation supported the development of a new, online Compendium of Financing Options for Long-Term Care Services and Supports, which provides a comprehensive overview of the public and private financing solutions proposed over the past three decades that can help inform current and future policymaking. We hope it can serve as a helpful resource to support Congress as it considers policies to bolster the long-term care and HCBS systems.

Incorporating Lived Experience in Policy Development

TSF strongly believes that policies and programs designed for older adults and people with disabilities *must* be informed by their lived experiences. Health and aging policies are usually designed from the system perspective, rather than that of the person receiving the care. Research and policy development on older adults often fails to meaningfully incorporate their direct feedback, and only rarely prioritizes the voices of underserved populations.

To address these shortcomings, The SCAN Foundation, in collaboration with the Public Policy Lab, built an online qualitative database of older adult interviews called *The People Say*. This tool is designed to ensure that the lived experiences of underserved older adults, including those of color, those who are low income, and/or those who live in rural areas, are captured, coded, and tied to relevant policy and program topics, such as transportation, care navigation, financial supports, and more. *The People Say* has data from over 140 interviews with older adults and their caretakers talking about their lives and what matters most to them. It is designed in a user-friendly way so that those creating and refining policy, programs, or practices, including access to HCBS and supports for caregivers, can easily search for and access targeted multimedia that speaks to the unique perspectives of older adults and caregivers.

On *The People Say*, there are many examples of older adults describing their experiences with LTSS and HCBS. For example, one older adult from urban California tried to get in-home services but, in her words, "*It was almost impossible to find someone, and it was impossible for me to keep following through. I surrendered*." This story is all too common among older adults, most of whom have to rely on family members to provide unpaid care or provide it themselves. As Anna, from Louisiana, who cares for her husband, explains, "*I have to take care of myself and also take care of him [my husband]. And taking care of him is is a job by itself, because I have to make sure he take his medicine and make sure he take a bath, just make sure he eats, and it's hard.... If I go somewhere, I have to take him with me.*" Stories like these demonstrate that there is a need for policies involving LTSS to more intentionally solicit older adults' real-world experiences. As another interviewee powerfully stated, "*Until you are there as an older adult or you are taking care of an older, elderly parent, you have no idea what that world looks like. And you didn't know how they got there or how you got there. And so for policymakers, they really need to be in tune with what they don't see. How can you be in more tune to what you don't see? And are you asking questions of those who are not the ones who are speaking up for themselves?*".

Multiple and Sometimes Conflicting Definitions of "HCBS" Can Frustrate Policy Progress

The absence of a clear, universally accepted definition for HCBS creates barriers to service alignment, quality measurement, cross-agency planning, and coherent policymaking. This definitional variability undermines efforts to answer essential questions about HCBS, such as: "What works, for whom, and in which circumstances?" Without clarity on the elements, values, and intended outcomes of HCBS, systems struggle to coordinate services, measure impact, and

direct resources equitably—particularly for underserved populations, including older adults with lower incomes and those living in geographically isolated regions.

The SCAN Foundation believes that establishing a shared understanding of what HCBS encompasses—and highlighting the current inconsistencies in how it is defined— will strengthen efforts to improve HCBS and help ensure that organizations, policymakers, and individuals are pushing for progress with a unified voice. To this end, The SCAN Foundation is exploring work around how best to create a consensus definition for HCBS, and we look forward to sharing findings with the Committee and other stakeholders in the future.

Leveraging Multi-Sector Plans for Aging (MPAs) to Support Community Living

Some states are using Multi-Sector Plans on Aging (MPAs) to find creative solutions to help their older adults age in place. MPAs are cross-sector policy and program blueprints that help improve coordination across state policymakers and private stakeholders to ensure older adults can live with dignity in the setting they choose. For example, implementation of California's MPA has improved access to HCBS by using data-driven analyses to identify gaps in both Medicaid and non-Medicaid services, and by implementing programs like CalAIM's Community Supports and Enhanced Care Management to address social needs and complex care transitions. 12 states currently have MPAs in place, and many more are actively exploring creating their own. Drawing from state MPA progress, there have been encouraging federal efforts to create a national plan on aging as well, both at the congressional and administration levels.

Keeping Older Adults at Home Makes Economic Sense

In the year of the 60th anniversary of the three cornerstone programs that have shaped aging in America—Medicare, Medicaid and the OAA—it is important to reemphasize how import these programs help older adults and people with disabilities stay at home and save the government money in the process. For instance, every dollar invested in services through the OAA generates a $3.39 return on investment. Ensuring robust funding for programs like HCBS helps prevent costly acute-care use, keeps family caregivers in the workforce, improves quality of life, and strengthens the broader economy by supporting a healthier, more stable older population. Studies have found that caregiving responsibilities have reduced work productivity by one-third, hurting the economic stability of the caregiver and their family as well as the overall economy. Protecting these programs is not only important for individuals' well-being but also carries significant economic benefits.

Conclusion

Thank you for the Committee's continued interest in home- and community-based care and the work you are doing for the for the millions of Americans that use Medicaid HCBS and OAA programs. Additionally, we commend the Committee for continuing to elevate the lived experience individuals at its hearings. We look forward to our continued collaborations with the Committee and elevating the voices of older adults in policy and program development.

U.S. Senate Special Committee on Aging

"Aging in Place: The Impact of Community During the Holidays"

December 3, 2025

Statements for the Record

Additional Statements

Senate Special Committee on Aging:

A Very Special Place, Inc is a not for profit located in New York and I have worked in the field of IDD for over 30 years and have had the great pleasure of providing to support to people in the field some who require little to no oversight where they live in their own apartment or home with Com Hab, Supportive Apartments to Supervised IRAs. Those who are fully employed, with coaches or those who need daily support in life and attend Day Habs.

When it comes to aging the most prominent story we can tell is one of a gentleman, for the purpose of this writing I will call Sam. Sam lived at home with his family and through the Day hab program gained the skill set to move into a Supportive Apartment with minimal staffing and 2 roommates in the apartment. He utilized supportive employment 2 days a week and 3 days a week in Day Hab to continue expanding his skills. At the age of 38 his friends from his apartment and program came to us and stated something was going on with Sam he needed assistance with dressing, remembering he was cooking, getting ready for work, etc. After a few appointments it became clear he had the onset of dementia/Alzheimer's.

Sam now required a higher level of care, we assisted him into moving into one of our Supervised IRA's where there would be 24-hour staffing, he could no longer work and would be very agitated or confused with people he did not know. His comfort and memory were better in his Day Hab program with the routine and familiar faces. He currently attends and has difficulty but with full staffing and his friends he still participates to the best of his abilities in the community, with learning, and having fun. It is 5 years since his symptoms started and while he continues to regress by forgetting how to walk, talk, eat at times direct care staff and the nurses work with him daily at home and in program to assist him in maintaining as much as he can.

At all stages in life everyone needs assistance and we have seen here at AVSP, Inc more and more those with IDD/downs syndrome having dementia/Alzheimer's begin by 40. This creates a larger challenge for all. While they may have been very independent prior, the skill set declines and declines quickly. However with routine, friends and consistent staffing by going to program, being in a supervised setting that is conducive to not only dementia/Alzheimer's but to IDD field their life is still productive and inclusive.

The challenges we face are that so many want to close the programs and supervise IRAs, yet where do people like Sam go? Family is unable to care for him as they are older, and he becomes agitated and at times aggressive when he is confused with daily tasks. Does he go to a nursing home where the level of care for those with both IDD and dementia are not

provided the same level of support and knowledge as being in the Day Hab or the Supervised IRA?

OPWDD and the state need to realize if person centered then at each stage in a person's life the need, level of care and the friendships with those they live, work or attend program with assist in making their life fuller.

Aging does not mean a certain age when someone is considered older, it is when the need for assistance is greater and like everyone in life this may require staff, aid, supportive living, a home, etc. No one should have a choice in where they want to live and what they want to do during the day/evening. We request that the committee look at the whole picture of someone's life and all the level of challenges a person with IDD may face and ask them what they want, what works best to assist them. Speak to the families and the staff of people who receive all different types of services at different points in the persons life so a full option of choices and opportunities can be made available.

Thank you

Jacqueline Scarcella

Executive Director

AVSP, Inc.

Alzheimer's Association and Alzheimer's Impact Movement Statement for the Record

United States Senate Special Committee on Aging Hearing on "Aging in Place: The Impact of Community during the Holidays"

December 3, 2025

The Alzheimer's Association and Alzheimer's Impact Movement (AIM) appreciate the opportunity to submit this statement for the record for the Senate Special Committee on Aging hearing "Aging in Place: The Impact of Community during the Holidays." The Association and AIM thank the Committee for its continued leadership on issues important to the millions of people living with Alzheimer's and other dementia and their caregivers. We especially recognize the significant role that social isolation, senior loneliness, and limited community connection play in shaping outcomes for people living with dementia — challenges that become more acute during the holiday season. Among other issues, this statement highlights the value of long-term care settings as well as home- and community-based services (HCBS), helping individuals living with Alzheimer's and other dementia remain in their homes as long as possible.

Founded in 1980, the Alzheimer's Association is the world's leading voluntary health organization in Alzheimer's care, support, and research. Our mission is to eliminate Alzheimer's and other dementia through the advancement of research; to provide and enhance care and support for all affected, and to reduce the risk of dementia through the promotion of brain health. The Alzheimer's Impact Movement is the Association's advocacy affiliate, working in a strategic partnership to make Alzheimer's a national priority. Together, the Alzheimer's Association and AIM advocate for policies to fight Alzheimer's disease, including increased investment in research, improved care and support, and the development of approaches to reduce the risk of developing dementia.

The burden of Alzheimer's on individuals and families continues to grow. Over 7 million Americans aged 65 and older lived with Alzheimer's dementia in 2024. Total payments for all individuals with Alzheimer's or other dementias are estimated at $384 billion (not including unpaid caregiving) in 2024. Medicare and Medicaid are expected to cover $246 billion or 64 percent of the total health care and long-term care payments for people with Alzheimer's or other dementias, which are projected to increase to more than $1 trillion by 2050. These mounting costs threaten to bankrupt families, businesses, and our health care system. Unfortunately, our work is only becoming more urgent.

Some researchers have surmised that factors such as social isolation from COVID-19 lockdowns, for example, no-visitor policies in long-term care facilities, and increased intensive hospitalizations may increase dementia risk at the population level, but research in the coming years will be necessary to confirm this and examine whether the impact is time-limited or long-term. Community connection is a critical part of both care and prevention.

We encourage the Committee to keep the following recommendations in mind to strengthen the support of the growing number of families affected by Alzheimer's, especially given the unique challenges the dementia care community faces in HCBS and long-term care settings. In

particular, efforts to reduce social isolation and address senior loneliness must be centered as essential components of high-quality dementia care and successful aging in place.

Use and Costs of Long-Term Care Services

Long-term care services include home- and community-based services and services delivered in assisted living residences and nursing homes, and the costs have grown consistently across settings. In 2023, nonmedical home care cost a median of $33 per hour and $6,292 per month, while homemaker services averaged $30 per hour and $5,720 per month. The median cost of adult day services was $95 per day. Assisted living averaged $5,350 per month, or $64,200 per year. Nursing homes were the most expensive: a private room averaged $320 per day ($116,800 per year) and a semi-private room averaged $285 per day ($104,025 per year). Few individuals with Alzheimer's or other dementias have sufficient long-term care insurance or can afford to pay out of pocket for long-term care services for as long as the services are needed.

The fourth most common chronic condition in participants using adult day services is Alzheimer's disease or other dementias, and 25 percent of all individuals using adult day services have Alzheimer's or other dementias. Fourteen percent of adult day service centers in the U.S. specialized in caring for individuals with Alzheimer's disease or other dementias in 2020, up from 10 percent in 2016. These services are also essential in combating senior loneliness by creating reliable touchpoints for social interaction and community engagement. By prioritizing policies supporting caregivers and combating social isolation and senior loneliness, we can help the aging population live longer, healthier lives.

Numerous states have recognized the importance of prioritizing dementia care coordination as part of a comprehensive system of diagnosis, treatment and care. Following a model set by Wisconsin, states such as Georgia, Indiana, Maryland, South Carolina, and Louisiana have established Dementia Care Specialists Programs. The Alzheimer's Association was proud to support each state in advancing these efforts and has ensured newly employed dementia care specialists have the training needed to effectively support people living with dementia and their families. All of these states have appropriated state funds to bolster their existing Aging or Public Health infrastructure with dedicated staff to provide community education, support families through the diagnosis process and connect individuals and caregivers to resources. States like Tennessee, Kentucky and Nevada have utilized limited federal grant funding in similar ways. In Florida, for example, the Florida Alzheimer's Center of Excellence (FACE) helps people with Alzheimer's and other dementias age in place and helps support families by bolstering support for caregivers. With trained specialists, families can access support to access a diagnosis and care, and get connected to clinical trials.

The Impact on Family Caregivers

While 83 percent of the help provided to older adults in the United States comes from family members, friends, or other unpaid caregivers, nearly half of all caregivers who help older adults do so for someone with Alzheimer's or another dementia. Of the total lifetime cost of caring for someone with dementia, 70 percent is borne by families — either through out-of-pocket health and long-term care expenses or from the value of unpaid care. Unpaid caregivers provided care valued at more than $22 billion in each of the four most populous states — California, Texas, Florida and New York.

Caregivers for those living with Alzheimer's face substantial challenges. Compared with caregivers of people without dementia, twice as many caregivers of those with dementia indicate substantial emotional, financial, and physical difficulties. These challenges are often magnified during the holiday season, when disruptions in routine and reduced support can increase caregiver stress and exacerbate social isolation. Of the unpaid Alzheimer's and dementia caregivers, 86 percent have provided care for at least the past year, and well over half have been providing care for four or more years. Approximately one-fourth of Alzheimer's and dementia caregivers are "sandwich generation" caregivers — caring for both someone with the disease and a child or grandchild.

People living with dementia and their caregivers often prefer to keep the individual living in the home for as long as possible, and HCBS allow people with dementia to remain in their homes while providing family caregivers with much-needed support. These services empower caregivers to provide quality care for their loved ones while giving them an opportunity to manage and improve their own health. They also help reduce caregiver isolation — an often-overlooked challenge that affects emotional well-being and the sustainability of care.

Given the demands and responsibilities placed on caregivers, respite is critical to their health and well-being, and may allow individuals with dementia to remain in the home longer. The use of respite care by dementia caregivers has increased substantially, from 13 percent in 1999 to 27 percent in 2015. Yet the availability of respite programs in the community is limited. We are proud to support the bipartisan Lifespan Respite Care Reauthorization Act of 2025 (S. 830/H.R. 2560), led by Senators Susan Collins (R-ME) and Tammy Baldwin (D-WI), and Representatives Nick Langworthy (R-NY-23) and Jill Tokuda (D-HI-02), to meet this growing demand.

One way the Association is helping caregivers of individuals with Alzheimer's is by providing a 24/7 Helpline (800.272.3900) available around the clock, 365 days a year. Through this free service, specialists and master's-level clinicians offer confidential support and information to people living with dementia, caregivers, families, and the public. The Full-Year Continuing Appropriations and Extensions Act (P.L. 119-4) allocated $2 million for the Alzheimer's Call Center, and we look forward to working with the Committee to continue funding this vital resource to individuals living with the disease as well as their caretakers.

Strengthening the Direct Care Workforce

As we enter a new era of Alzheimer's treatment, access to timely and accurate detection and diagnosis is more critical than ever. And as the prevalence of Alzheimer's disease increases, so does the need for members of the paid dementia care workforce. Nearly 900,000 additional direct care workers will be needed between 2022 and 2032 — more new workers than in any other single occupation in the United States. For example, in New York, nearly 13 percent of all individuals aged 65 and older have Alzheimer's disease, and a nearly 29 percent increase in the workforce is needed to meet the expected demand in 2032. And in Florida, meeting the expected demand in 2050 would require an increase of over 168 percent. Meeting this demand requires a collaborative, multidisciplinary workforce that includes primary care providers, neurologists, geriatric specialists, registered nurses, social workers, and direct care professionals such as personal care aides, home health aides, and nursing assistants. Each plays a critical role in identifying cognitive concerns, diagnosing and treating the underlying cause, monitoring disease progression, and delivering hands-on care and support across the disease continuum.

Beyond these distinct tasks, direct care workers play a broader role in promoting nutrition, exercise, functional ability, social engagement and emotional well-being for those living with dementia. With training in active listening, empathic response and other relevant skills, direct care workers can reduce social isolation and provide emotional support and, with additional training, help prevent or reduce distress associated with dementia through the delivery of person-centered, non-pharmacological interventions. Their daily presence is often one of the most consistent sources of social connection for individuals with dementia aging in place.

Technology-enabled collaborative learning and capacity-building models, like Project ECHO, use a hub-and-spoke approach by linking expert specialist teams at a 'hub' with the 'spokes' of health providers in local communities to increase on-the-ground expertise. Using case-based learning, Project ECHO models can improve the capacity of providers, especially those in rural and underserved areas, on how to best meet the needs of people living with many chronic conditions, including Alzheimer's and other dementia. The Alzheimer's and Dementia Care ECHO program, led by the Alzheimer's Association, has trained more than 2,000 health care professionals since 2018. Ninety-five percent of those professionals made changes to the way they care for patients as a result of what they learned from ECHO. Quality care delivered by trained providers leads to better health outcomes for individuals and caregivers and puts less strain on health systems. Project ECHO programs have shown they can help address the knowledge gaps felt by many primary care providers. Legislation like the bipartisan Accelerating Access to Dementia and Alzheimer's Provider Training (AADAPT) Act (H.R. 3747) would expand access to high-quality virtual dementia education and training programs - addressing knowledge gaps, building workforce capacity, and empowering primary care providers to better diagnose and care for people living with Alzheimer's and other dementias. These programs are designed to be nimble, allowing new diagnostics and therapeutics - like recently approved blood-based biomarker tests - to be quickly integrated into training as they become available.

The *Alzheimer's Association's Dementia Care Practice Recommendations* include the following recommendations specific to workforce: (1) staffing levels should be adequate to allow for proper care at all times — day and night; (2) staff should be sufficiently trained in all aspects of care, including dementia care; (3) staff should be adequately compensated for their valuable work; (4) staff should work in a supportive atmosphere that appreciates their contributions to overall quality care because improved working environments will result in reduced turnover in all care settings; (5) staff should have the opportunity for career growth; and (6) staff should work with families in both residential care settings and home health agencies. Additionally, we know that consistent assignment is an important component of quality care for staff working with residents with dementia.

While much of the training for long-term care staff is regulated at the state level, we encourage the Committee to consider proposals that support states in implementing and improving dementia training for direct care workers, as well as their oversight of these activities. Training policies should be competency-based, should target providers in a broad range of settings and not limited to dementia-specific programs or settings, and should enable staff to (1) provide person-centered dementia care based on a thorough knowledge of the care recipient and their needs; (2) advance optimal functioning and high quality of life; and (3) incorporate problem-solving approaches into care practices.

We also urge the Committee to support states in the following efforts: (1) any training curriculum should be delivered by knowledgeable staff that has hands-on experience and demonstrated competency in providing dementia care; (2) continuing education should be offered and

encouraged; and (3) training should be portable, meaning that these workers should have the opportunity to transfer their skills or education from one setting to another.

The Alzheimer's Association and AIM look forward to working with the Committee to shape specific proposals to better train and support the direct care workforce to provide the highest-quality support for individuals living with dementia.

Conclusion

The Alzheimer's Association and AIM appreciate the steadfast support of the Committee and its continued commitment to advancing issues important to the millions of families affected by Alzheimer's and other dementia. We look forward to working with the Committee in a bipartisan way to address the challenges facing the dementia community.

Martha Kemmer-Contreras, works for a service provider in a role other than direct support
Karl's Story
Cheyenne Village
Colorado Springs, Colorado

A community's strength is reflected in how it supports people across their entire lifespan, especially adults with I/DD. When programs are built to grow with a person, they offer not just care, but a lifelong foundation of confidence and connection. Karl's experience illustrates the profound impact of being supported every step of the way.

Karl's Journey Home

Karl arrived at Cheyenne Village, Inc. in Colorado Springs, in 1975 at just 22 years old and unsure of what life would hold. What he found was people who believed in him. The staff saw possibility—little sparks of independence waiting to be nurtured.

Karl learned things that would shape the rest of his life. He learned how to cook simple meals, how to keep his room tidy, and how to speak up when he needed help. He discovered that he loved the satisfaction of mastering new skills. His world grew larger, and so did his confidence.

When the Manitou Springs location of Cheyenne Village eventually closed, Karl didn't lose his home—he simply stepped into the next chapter. By then, he had learned so much that the idea of living in an apartment didn't feel impossible. It felt right. Paired with a roommate and supported by Cheyenne Village's dedicated staff, Karl found a rhythm to his days: grocery shopping trips, afternoons watching his favorite shows, evenings filled with small victories in independent living. His apartment wasn't just a place to stay. It was a home he helped shape.

As the years passed and Karl grew older, his needs changed. When it was time for more support, Cheyenne Village didn't let him face that transition alone. They found him a host home—a family who welcomed him not just with open arms, but with open hearts. In that household, he had a seat at the dinner table, celebrations to look forward to, and people who cherished him. He became part of their story, and they became part of his.

In time, Karl's health required even more care, and once again Cheyenne Village was there, guiding him gently to the next place he needed to be. He moved into a group home with 24/7 support, surrounded by caring professionals who knew his history, respected his journey, and honored his life.

Through every chapter—each change, each new beginning—Karl never walked alone. Cheyenne Village was his constant: supporting him, empowering him, and ensuring he always had a place where he belonged.

And in each of those places, Karl left behind a legacy of quiet courage, resilience, and the simple, profound truth that every person deserves to grow, to be seen, and to be loved across a lifetime.

Becky Baily, works for a service provider in a role other than direct support
Center for Independent Living
Hansen, Idaho

My name is Becky Baily. I have worked previously in intermediate Care facilities for I/DD. I began my career 35 years ago. In 2010, I started working solely with Home and Community Based Service setting (supported Living/Res Hab, Community supported employment, Developmental Therapy).

The difference I have seen in people's health, treatment, and the quality of their lives is staggeringly different with HCBS services. Please help to protect these services which are paid for only with Medicaid funds. HCBS services cost less than traditional institutional settings and allow people to live as human beings with the freedoms to choose things in their lives as other nondisabled people have enjoyed for much longer.

I welcome a tour of any legislator from Idaho's Capitol to Congress.

Sincerly,

Becky

Brad Harvey, a person who receives I/DD services
CIL
Twin Falls, Idaho

My sister helped write about me.

Brad was born with a severe seizure disorder and has struggled his entire life. He was put into the Nevada State Hospital when he turned 14.

As an adult, Brad was finally able to move into a group home in Reno. It was better than an institution, but still not an ideal life. After many moves to many group homes over the years, we decided to move him to Idaho, where my husband and I live.

He is now living a full life at the age of 76. He makes all his own choices. He chooses his meals and decides when to eat them. He has excellent health care. We have NEVER seen Brad this happy. He has a cute sense of humor, which showed itself when he moved to Idaho. We want Brad to remain in this situation for the rest of his life.

~ Nancy, Family Member, Eagle

Tom Davis, a person who receives I/DD services
CIL
Twin Falls, Idaho

My sister, Carolyn helped write my story.

Tom is developmentally disabled with partial paralysis. He is unable to transfer and requires full-time care and assistance, and lives in a group independent living home.

Tom receives Medicaid services for all his care, living expenses, and medical bills

Without Medicaid, our family would not be able to physically care for Tom.

~ Carolyn, Familly Member, Twin Falls

Matthew McKenzie, a person who receives I/DD services
CIL
Twin Falls, Idaho

I am a 44-year-old man with Down Syndrome, chronic lung failure and type 1 diabetes. I live in Twin Falls, ID in a Medicaid supportive Residential Habilitation home. This program provides me with a wonderful and productive life. I live in a home with other adults with disabilities that are like family to me. The staff are outstanding! They assist with all the medications and activities of daily living and drive me to my doctor's appointments.

Without Medicaid, I would not be able to sustain my home, medication, and medical care. This would have detrimental consequences on my livelihood. Please consider the disability population that requires these Medicaid programs to live and thrive in their communities. This not only helps the disabled population, but they give back to their communities by working, supporting the economy, loving the stranger, sharing their God given gifts to the communities they serve, like art, music, and educating the general public that life is good and to be grateful for who you are. Our lives are a delicate balance of fortitude in the balance of justice, and liberty for all peoples.

~ Matthew, Twin Falls

Diane Hammond, parent of a person who receives I/DD services
Polk City, Iowa

Hello,

Our daughter Madison is soon to be 25. She gives the best hugs she has a diagnosis of Intellectual Disability and Down Syndrome. We were fortunate to not have to wait for services for her. From early on we were able to provide Madison with a variety of services to help her to grow and learn. We had speech therapy, OT, PT along with case management. All of these opportunities gave Madison a strong foundation. She has worked with some of the best. We were lost in the beginning but because of the resources made available to us as parents we learned so much and continued to find resources as she grew up through school.

But not only did it impact us, but turns out other peers were learning and growing in positive ways to interact with someone who may not look like them. Madison did studio dance with typical peers, horseback riding and was on Homecoming court. Since she graduated we have been fortunate enough to find her a home with Friendship Ark. Without this resource Madison would be sad. She likes living in a home with other core members. Staff are amazing. Please think of Madison and all others that need these services when it comes time to make decisions.

Thank you for taking the time to read this.

Sincerely,

Madison's mom Diane

Gary Eyles, parent of a person who receives I/DD services
Ames, Iowa

My daughter has intellectual disabilities and challenges. She currently lives in a group home through Friendship Ark, Inc. located in Ames, Iowa. The support she receives has been transformational in helping her develop independence and basically feeling more like a young adult. Moving out of her family home was difficult (mostly for us parents) but the staff that interact and look after her have been fantastic and it has reassured us that the move was the right thing. Our daughter continues to flourish and is surrounded by love and support 24 hours a day, seven days a week. Our daughter is in her last year of high school and we feel much more confident about the next chapter of her life largely due to to the assistance and supervision of Friendship Ark.

The services that organizations like Friendship Ark provides are invaluable for the intellectually and physically challenged citizens of our communities. Members are able to thrive through being active in social and work settings so that individuals feel being important and valued members of their communities. HCBS services are crucial to enriching our daughter's life each and every day. Please continue to support community living for older adults and people with disabilities. I encourage you to go visit a home and you will see the massive impact these services have. Thanks.

Mark Mallas, parent of a person who receives I/DD services
Granger, Iowa

Friendship Ark has been a blessing for our family and daughter. She loves living at her HBCS waiver home and I couldn't think of a better place for her to be. When I take her on visits she always talks about all the great things she is able to do at her house along with all the community outings she participates in. Our visit is mostly short lived as she asks when she can go home, which warms my heart as I know she is being well taken care of. I don't know what I would do without Friendship Ark!

Sydney Dighton, works for a service provider in a role other than direct support
Seth's Story
One Vision
Clear Lake, Iowa

Seth was part of One Vision's Smart Living pilot program. He was living in a traditional HCBS home with 24/7 direct care. Seth flourished with this service model, and after a few months he began advocating for himself to have his own apartment with remote services.

Seth now uses a combination of HCBS and Smart Living remote support to live safely and independently in his own apartment. Because of this blend of services, he works in the community, manages his home, and participates in activities that matter to him — all while knowing support is there when he needs it.

Smart Living technology gives Seth reminders, safety monitoring, and access to remote staff 24/7, but it doesn't replace human support. His DSPs still help him build skills, make decisions, solve problems, and stay connected to his community. With this support, Seth has grown in confidence, learned to manage his schedule, and even navigated transportation barriers that once kept him isolated. An often unrecognized benefit of the support Seth and others receive is the impact it has on their relationships with their loved ones. Seth's relationship with his family has improved as he gains more confidence and is able make decisions on his own.

If HCBS or Smart Living supports were limited, Seth would lose the independence he has worked so hard to gain. He would likely require a more restrictive, more expensive care setting that would limit his ability to work, live where he chooses, and stay engaged in community life.

HCBS — enhanced by the tools of Smart Living — helps Seth not just live safely, but thrive.

Sydney Dighton, works for a service provider in a role other than direct support
Courtney's Story
One Vision
Clear Lake, Iowa

Courtney and her beloved dog, Zeva, lived in a home with other individuals and received direct support twenty-four hours a day, seven days a week. Zeva had to be removed from the home and this greatly impacted Courtney's well-being. Courtney now lives in her own home with the help of Home and Community-Based Services (HCBS) and Smart Living remote support, a combination that lets her stay independent, connected, and in control of the life she chooses — including keeping her dog, Zeva. She recently started working at a job she found through One Vision's Employment Services.

With remote support, Courtney can check in with trained staff at any time, receive reminders, and access support to problem-solve at home without losing her privacy or her freedom. Her DSPs visit regularly to support her with budgeting, appointments, and household tasks, while the remote team is available when unexpected needs come up. This blend of support gives her safety without sacrificing autonomy.

Because her services come to her, Courtney doesn't need to move into a congregate setting where pets are often not allowed. She keeps her home, her routines, her job, her community connections, and her four-legged companion — all of which are essential to her wellbeing.

If HCBS or remote support were reduced or eliminated, Courtney's independence would be at risk. She would likely need a more restrictive environment that would separate her from her home and from Zeva, and limit the choices she is able to make for herself.

Community-based services don't just keep Courtney safe — they let her live life as Courtney, surrounded by the people, places, and experiences that bring her joy.

Cathy Martin, parent of a person who receives I/DD services
Ames, Iowa

My adult daughter Julia has intellectual disabilities. Without community based support she would not be able to live independently. She receives help with many things including transportation, grocery shopping and meal prep but even more importantly she receives emotional, social and behavioral support.

Her service providers are Friendship Ark and Mainstream Living.

I don't know what she would do without the services she receives.

Greg and Shari Hampton, parents of a person who receives I/DD services
Friendship Ark
Clear Lake, Iowa

At the age of 12, our adopted son's mental health issues reared their ugly heads. We were no longer able to keep him or ourselves safe at home. By the age of 16, his meds and therapies were balancing him and he moved into a special home. A home. Not a facility. Not an institution. He got a new family. A group of people that also needed help. Special others to help and Support them. When people tell us how special our son is, we tell them that Friendship Ark raised Matthew well.

He has grown into SCL with the help of the same team who has been there for him for 20 years. It says a lot that some are the same people he started with. Matthew knows without his meds and without his supports, he will once again be violent. He fears being in prisons and institutions as his bio parents were. He fears becoming a homeless person. He worries about all of those in his extended family and community who might fare even worse than he.

We are grateful to the supports for helping Matthew grow into a loving and caring person, capable of having his own apartment and a part time job. Supporting him in his daily life. Matthew receives job coaching and it is incredible. He has a payee that makes his financial life doable. We feel communities will deal with much more homelessness if these services are gone. Law enforcement will be overwhelmed and jails will be fuller. Lives will be empty. Lives will be lost.

Carley Garrett, a person who receives I/DD services
Big Lakes Developmental Center
Manhattan, Kansas

It is impactful because Big Lakes provides services for people with intellectual disabilities. It is important to me because for having help with doctor appointments, questions about jobs, and a place where I can live. It has helped me with work because the contract work is done at the workshop where I feel comfortable before being in the community. I am in job skills to build skills before working in the community.

My guardian, family, case manager, staff, and friends help advocate for me. If services were taken away it would be really hard because I could not live with my family or by myself and would have no where to go. Staff during day services and residential services have helped me with advocating for myself and improve my social skills.

Karl Drown, a person who receives I/DD services
Big Lakes Developmental Center
Manhattan, Kansas

It is really a big impact because the staff help us with our emotions and anything that we need. The staff helps with our problems we are having. The staff help us with transportation. I am able to make new friends. I like the summer and winter parties with staff and my friends.

Services teaches me how to be independent and I can get paid for the contract work that I do at the workshop. If services were limited or taken away it would completely mess up my life. The services help me control my anger, my work, and my whole life.

The services are like family to me. If I did not have them I would have nothing. Staff has been helpful and has good personalities. The staff takes the time to get to know me and how to help me. Staff are the best people. I cannot make it in life without my staff and services.

Chelsea Kubin, a person who receives I/DD services
Big Lakes Developmental Center
Manhattan, Kansas

Services helps us communicate with other people like us. Been in services for 2 years has changed my point of perspective in being here. It feels like I am more independent. The staff encourage clients to improve their coping skills. If services were taken away it would be very hard and I would not be able to do the stuff that I am able to do now. I want to say thank you to Big Lakes for being here for me.

Emily Lutz, a person who receives I/DD services
Big Lakes Developmental Center
Manhattan, Kansas

Big Lakes has made me gain my independence and I consider Big Lakes my family. I have friends in services with me. I get to meet new people in the community through work. I am able to access the community like going out to eat with my friends. I am able to spend time with those that I love. My social skills have improved with being in services and I am happier than I was before.

Before Big Lakes I was depressed and always wanted to stay home. Now with Big Lakes I want to be out and with my friends. If services were limited or terminated, I do not know where I would live or spend my days. The staff have trained me how to work in the community and how to improve on my work skills and independence. I am very blessed to have Big Lakes in my life and I do not know what I would do without them because it is so important to me.

Mitchell Benson, a person who receives I/DD services and works for a service provider in a role other than direct support
CCRI
Moorhead, Minnesota

When I was 23 years old, I suffered a spinal cord injury, paralyzing me from my shoulders down and without the use of my arms or legs. Prior to that I had already graduated college and was working a job in construction. I was very physically capable and could independently do practically anything. Since my accident I have been physically dependent on direct support professionals for most aspects of my life: feeding, bathing, repositioning, going to the bathroom… Etc. Cognitively or intellectually, I have no issues, but my body just does not work.

Prior to my accident I would not have thought life in this situation could be anything more than living in a nursing home waiting for friends or family just to stop by and visit you. I imagined living with people decades older than me, watching life pass me by.

Thankfully I was wrong and I found a home in CCRI. CCRI provides 24-hour care through community-based services. Aside from just my care, my caregivers make it possible for me to continue living life outside and in the community. Taking me out to: visit family, instead of the other way around, hang out with friends, go to sporting events or movies. I'm able to work, go hunting and experience nature. With the assistance of my caregivers, I have had a garden for the past eight or nine years, and we annually make my homemade salsa. The spicier the better! I have found a love for cooking and experimenting with new recipes in the kitchen and out on my smoker. With the support of some of my talented caregivers I even took up drawing, with my mouth. It's a work in progress but some of it has turned out surprisingly good. CCRI allows me the opportunity to try anything my heart desires, within reason, and that's all that anyone can hope for in life.

I navigate the world with power wheelchair that I operate with my head. Utilizing assistive technology and vocational rehab services I was able to go back to college and earned a bachelor's degree in business administration, graduating summa cum laude. I found I was more intellectually capable than I had previously given myself credit for. Nine years, to the day, after my accident, I rejoined the workforce. This month I just celebrated my 10th anniversary working for CCRI. My body doesn't handle full-time work, but I do work part time in the HR department.

If you didn't catch it, I work for the provider of my services, in the HR department. I have a unique perspective of seeing the shorthanded workforce from the outside and experiencing it on the inside. Turnover for DSPs in this industry is over 50%. Finding quality caregivers is hard and keeping them is harder with the job itself coming with being shorthanded. I've had some pretty good caregivers over the years that have impacted my life enough to where I consider them family. The good ones are always picking up the slack but that can lead to burnout. Can you imagine depending on someone when you know they're burnt out?!

I should specify, I do live in a house with three other individuals with disabilities. Collectively it can be a lot, and we have to balance with a limited number of caregivers. From my successes listed you can see CCRI does a good job, but they could always use better wages to attract more quality staff. 90% of the funding for wages are provided by the state. There are many other providers with many more individuals with disabilities depending on services like mine. We don't need less services, we need more! I currently have a couple friends that are on wait lists to get into a community-based service provider. They are currently biding their time in a nursing home, and they are lonely and bored most of the time. Limiting or

cutting any part of these types of services would be detrimental to the lives of anyone who depends on them.

Right after my accident I never thought some of the things I've done would be possible again. Thanks to community-based service providers like CCRI I've been able to continue living life and trying new things. I don't know what my life would've been like without CCRI, but I can tell you it turned out far better than I imagined prior to needing these types of services.

On a side note, having a disability can come in any fashion. You can be born with one, suffer a neurological illness, have simple accident, or sometimes just aging roughly. My accident happened in the blink of an eye. Might want to keep that in mind in case you were to ever need services. I bet you'd feel more comfortable knowing that they're there.

Sincerely,

Mitchell Benson

Kristine Berger, a person who receives I/DD services
Great River Homes, Inc.
Wabasha, Minnesota

Twenty years ago, my case manager from another region reached out to Great River Homes, Inc. At that time, I was desperately searching for a residential community placement that could truly meet my needs and support my hopes for a better life. My quality of life was spiraling downward into a dark vortex of isolation and harmful choices. I was unable to maintain employment, and I had reached a point where I was no longer safe to be around others—nor were they safe to be around me. I withdrew from opportunities to engage with others, pushed away family relationships, and engaged in serious self-injurious and suicidal behaviors. I had become a "frequent flyer" with local mental health services and crisis homes. My life felt increasingly volatile when my case manager reached out to Great River Homes, asking if they might be willing to step outside their comfort zone to give me a fresh start in a new environment.

My team at Southern Cities Clinic, along with staff from the crisis home, developed a support plan to help stabilize my life and begin reversing the downward spiral. They provided extensive, ongoing, and invaluable training and support to the team members at Great River Homes as I transitioned from crisis care to my new community home in Wabasha. With their collaboration—and with the dedication of a compassionate and highly experienced team at Great River Homes—we navigated the complex twists and turns of my support needs together.

As I stabilized, I was able to reconnect with my family. My mom often remarked, with deep appreciation, how much more pleasant and meaningful our visits had become. I also built genuine friendships with my housemates, including one gentleman with whom I shared spirited discussions about the Minnesota Vikings and Green Bay Packers, farming, mutual friends, and cooking. My passion for living life was reinvigorated.

Over time, I grew more comfortable living in Wabasha, MN. I developed friendships with neighbors on all sides of my home, including a long-term friendship that brought comfort and companionship to a lonely, elderly neighbor.

With tears of heartfelt joy in her eyes, my longtime case manager—who had supported me through my most difficult years—recently told me she had never seen me so calm, proud, and happy.

In the twenty years since that pivotal moment, I have built a stable, meaningful, and enriching life. I've been gainfully employed, experienced genuine inclusion, and built a broad and supportive social network. The dark vortex that once consumed my life has transformed into a joyous and promising geyser.

Thanks to the intensive and compassionate support I've received through my Community Residential Home, I now have the tools and confidence to live safely and more independently. I participate in life on all levels where I am able to build new connections and have a sense that I truly belong. Securing my dream job working in a school with students has been a recent highlight. I enjoy giving back, so I participate in the fundraising activities that are meaningful to me, like the local Grumpy Plunge, by plunging into the Mighty Mississippi on the last Saturday in February. I could not be prouder of the person I've become. I often reflect on who I once was and recognize that I would not be where I am today without the incredible commitment and care of those who supported me along the way and those who support me today.

I know I am still a work in progress- aren't we all—but I refuse to let where I was define who I am today. MY community residential HOME is where my heart is.

Darlene Scott, works for a service provider in a role other than direct support
The Phoenix Residence Inc.
Saint Paul, Minnesota

The Vital Importance of Community Living for Individuals with Disabilities

Impact of Community-Based Services in Minnesota

- Community living allows individuals with disabilities, including those with ID/DD, to live close to family, friends, and natural support.
- For Kenyelle, who sustained a traumatic brain injury, community-based services allow her to stay near her five children and maintain emotional stability.
- Georgia, sustained a disability due to a car accident, benefited from being surrounded by family, contributing to her healing process and her sense of value being a contributing member in her household.
- Cody, who has had ID/DD since birth, thrives because he can live in a familiar community environment where he is valued and supported.

Community Services Supporting Education and Work

- Community-based services promote access to job training, day programs, and supported employment.
- Cody has participated in community employment programs, gaining skills and contributing meaningfully. Completed high school and enjoys the ability to engage in community activities in the neighborhood where he lives
- Kenyelle and Georgia can pursue personal development with the support of Direct Support Professionals.

Impact of Limited or Terminated Services

- Without community-based services, individuals may face institutionalization, which removes them from family and essential support systems.
- Loss of services may lead to reduced independence, isolation, and decreased access to employment and educational opportunities.

Positive Impact of Direct Support Professionals (DSPs)

- DSPs play a critical role in promoting independence, supporting daily living tasks, and ensuring community engagement.
- They support individuals in maintaining relationships, working, attending church, participating in recreation, and more.
- DSPs support health needs, safety, and improve the overall quality of life for individuals with disabilities.

Daniel S., a person who receives I/DD services
Center For Human Services, Inc.
Sedalia, Missouri

- **What is the impact of community-based services for people with I/DD in your community?**

  The services have been pretty good so far. They help me be the best person I can be. They treat me with respect which is very important to me. They help me grow.

- **How has access to community-based services allowed you or others to thrive in places like education and work settings?**

  Job Coaches help me be best employee I can be. Working is important to me. Making money to pay my bills is important to me. Job Coaches and Benefits Planners help me learn and grow…They help me meet my goals in life.

- **How did your life or the lives of others improve with access to community-based services?**

  Working with Job Coaches have helped prove to myself I can be a better person. It lets me earn money so that I can buy the things I want in life. And hopefully will eventually help me take the steps I need to be on my own someday.

- **How would your community be impacted if services were limited or terminated?**

  If I wasn't able to have these services, I would be sad and disappointed. Not having these supports would make my life harder. I would struggle with living and working – I would not be successful without these supports.

- **How have direct support professionals, or your work as a DSP, made a positive difference?**

  ES Staff supports me, they help make me be a better person. They help me be more confident and more independent.

AJ Private, a person who receives I/DD services
Center for Human Services
Sedalia, Missouri

- **What is the impact of community-based services for people with I/DD in your community?**

  They help you with your mental health issues and for moral support. I am able to have a day filled with activities and meet with my friends and otherwise I would not be able to.

- **How has access to community-based services allowed you or others to thrive in places like education and work settings?**

  They have helped me look at possible jobs in my community and I have friends that have jobs and they are able to do more and keep their benefits. They are made about me and the things I like and need.

- **How did your life or the lives of others improve with access to community-based services?**

  They get help, support, and education that we need to live on our own. Without services I would be lost and possibly not even here anymore.

- **How would your community be impacted if services were limited or terminated?**

  I would have to move and would lose my home and we would not have things to do or the support to do them. We would also lose jobs.

- **How have direct support professionals, or your work as a DSP, made a positive difference?**

  They provide me with someone to talk through issues with, support me to attend things I enjoy, and learn new things I did not know. They help me to go places I would not be able to do because I cannot drive. They make my life better!

Cindy D., a person who receives I/DD services
Center For Human Services, Inc.
Kirksville, Missouri

- **What is the impact of community-based services for people with I/DD in your community?**

  They help us with explaining things better, supporting us, help us learn skills to be more independent.

- **How has access to community-based services allowed you or others to thrive in places like education and work settings?**

  Having a job coach allows me to work in the community. They also help me with my training's and learn new skills in a work environment.

- **How did your life or the lives of others improve with access to community-based services?**

  Community-based services saved me. They allowed me to choose where to live and if I wanted roommates, or not.

- **How would your community be impacted if services were limited or terminated?**

  I wouldn't have the support that I needed to be successful in an work environment, everyday life, and living on my own.

- **How have direct support professionals, or your work as a DSP, made a positive difference?**

  They help me manage my money, live a healthy life, make the right choices, and takes me out in the community.

Geno Walters, a direct support professional
Dungarvin
Albuquerque, New Mexico

My Name is Geno Kirkpatrick Walters.

I work for Dungarvin in Albuquerque New Mexico providing Services to Individuals on The IDD Waiver Since 2015.

When I was asked the question about making a difference in someone's life I immediately thought of Cindy Lou. She was born in 1961. The day I met her and started providing services, I knew I was going to make a difference in her life. She resided in Belen New Mexico in 2019, but currently lives in Albuquerque New Mexico. During the transition I went to her house, met all her staff, and her old roommates. She is considered intensive Medical Care. While residing in Belen, and there were multiple occasions a month before being admitted in the hospital. Since coming under my care in 2019, she has not had any episodes.

At a point in time ,Cindy Lou was on hospice and I stayed strong to keep her strong ,happy and smiling. Eventually Cindy Lou graduated from Hospice not just due to the care we provide but the energy we release and natural care we share. Non-Verbal care is A Gift I received understanding not just the action they can give but also through the Eyes. If my client can only scream or yell, I listen to the Tone. They use different tones, like high pitch and low pitch. I listen and "figure it out by looking around the scenery" , and I speak to them. I know their gestures they give, and I figure it out. Cindy Lou remembers everything about my care like how my voice sounds and the rhythm of my foot steps. She can smell my cologne when I come in the room, and she screams with joy; she shouts out with her screams certain tone say "hi, come here , I hear you."

I look for those signs and on a rough day just knowing she is happy I'm back. She knows I'm on it. And her smile brightens up my day. Our best trips together were spent in Las Vegas Nevada and Durango Colorado, and we are currently planning a trip to San Antonio Morgan's Wonderland.

If the people I support suddenly lost access to the services I provide, this will cause Survival Mood, no more smiles, no trust; this will break the spirit their faith. Non-Verbal people can hear, and they can also feel, like a superpower. They "sense" when they are being treated fairly; there's good people They want to be treated equal treated as human being, not just someone with needs. My presence helps to heal, and it is a two-way street. These bonds can help and heal us all. My work is a gift I have and a gift I give freely. It is part of me to share with others. It comes back to me 10-fold.

Kathy Peterson Vanhorn, works for a service provider in a role other than direct support
The Resource Center
Jamestown, New York

I have worked at TRC for about 44 years in various jobs and feel that I am making a difference in the lives of the people I support. I run a self-advocate group called Voices for Choice which meets monthly to discuss and support many topics that come up. I have also had the pleasure of providing two other programs at TRC.

I had my dog Layla who was a peke come to work and dress up for every event which was featured in the Resource newsletter which was titled "Layla's Corner"! This went on for 3 years until Layla passed away last year. We currently have my dog Tobey a minnie Aussie Doodle who comes in, and he is in the newsletter for "Tobey Time". Tobey is currently taking classes through PetSmart to be some type of service dog. He is currently 18 months old. Layla was 17 years old when she passed and she was a Good Canine Citizen.

The purpose of bringing the dogs in is to give the persons that I support the chance to interact with a dog. This is what I do when I am not doing my job of interacting with the individuals that I support in our Day Hab Program which is very fulfilling. This is my story to share.

Barbara Bouchey, family member of a person who receives I/DD services
Saratoga Springs, New York



My name is Barbara Bouchey, and my brother Brian has Down syndrome. As he has grown older, Brian, like so many adults with Down syndrome, has developed Alzheimer's disease. He has lived in a supervised home with Living Resources for more than 25 years, and the care and stability he receives through home and community-based services (HCBS) have been nothing short of life-changing for him and for our family.

My brother Steven and I share guardianship of Brian, and we have seen firsthand how essential these supports are. The staff who care for him every day are the reason he can continue to live with dignity, comfort, and connection as his needs increase. They understand his history, his personality, his routines, and the subtle signs that help them respond before a small concern becomes a crisis. That is only possible with a stable, well-supported workforce.

Our family's relationship with Living Resources runs deep. My other brother, Danny, also received support from the organization and lived in one of their residences. The compassion shown to Danny, especially in his final chapter, stays with me. It is a reminder of how much these programs matter not only to individuals, but to the people who love them.

Yet for all that HCBS makes possible, we are facing a stark reality: our systems are not prepared for the aging of people with intellectual and developmental disabilities. This population is aging, living longer, fuller lives than ever before, and the infrastructure around them has not kept pace. Too many agencies lack the staffing, resources, training, and specialized programming needed to support adults who are facing complex conditions like Alzheimer's, mobility loss, dementia-related behaviors, and end-of-life needs.



Families like mine are deeply grateful for the services that exist, but we are also worried. Without sustainable funding, competitive wages for direct support professionals, and dedicated investment in aging-specific supports, the system will continue to strain under a growing need it was never built to absorb.

Brian has always been the heart of our family. Watching him age has been both painful and profound, but the one constant has been the care and compassion provided by the people who support him every day. HCBS isn't just a service; it is the difference between uncertainty and stability, between suffering and comfort, between isolation and a life still rich with meaning.

I am sharing Brian's story, and Danny's, because families like ours are counting on policymakers to act. The system must evolve to meet the needs of a population that is living longer than ever before.

Strengthening HCBS today is how we ensure safety, dignity, and hope for people with disabilities as they age, and peace of mind for the families who love them.

Respectfully,

Barbara Bouchey

Donald Mullin, works for a service provider in a role other than direct support
The Arc of Rensselaer
Troy, New York

I want to share the story of A, a man who came to us carrying the weight of severe trauma. In his early days, A's pain often showed itself in combative ways—he would knock out windows, frighten his housemates, and put staff at risk. The environment was unsafe for everyone, and the costs—both human and financial—were mounting.

With the support of Home and Community-Based Services (HCBS) funding, we were able to move A into a place of his own. The transformation has been remarkable. His tantrums have decreased, his sense of stability has grown, and he is thriving. The benefits ripple outward:

- His former housemates now live in comfort and peace.
- Staff injuries and turnover have dropped significantly.
- Emergency room visits and property damage are down.
- Staffing costs are lower, even in this smaller setting, because the environment is calmer and more sustainable.

A's story is not unique. It is a powerful reminder that regulations and larger congregate settings can sometimes unintentionally harm individuals who need personalized support. HCBS funding allows us to create environments where people can truly succeed—where dignity, safety, and community are possible.

HCBS funding is not just a budget line. It is a lifeline. It makes the difference between chaos and stability, between fear and hope, between surviving and thriving. We urge you to continue supporting HCBS so that these life-changing wins remain possible for A and countless others.

Thank you for your leadership and commitment to ensuring that every individual has the chance to live with dignity and opportunity.

Julie Herbst, works for a service provider in a role other than direct support
I AM Boundless
Miamisburg, Ohio

I work as a therapist with adults and children with intellectual and developmental disabilities. I have spent much of my life with this population. From volunteering with the county in high school, to working as a registered behavior technician, to what I do today. Additionally, I am a graduate student at Wright State and have many peers who are part of the I/DD community, and I personally have disabilities but don't receive services.

I have learned so much about life and about joy from the people I serve and interact with. I have also learned a fundamental truth across all human life: we all want connection. In working with community-based services, I have seen how true, meaningful connection is a huge factor in a person's resiliency, especially when looking at disability status.

My company strives to not only give our clients with I/DD a space to feel connected and welcomed but helps them to engage in the local community in ways that are meaningful to them. If we lose the ability for community, we lose sight of those who will suffer without it. They will be isolated and that is a factor that leads to depression, suicidal ideation and attempt.

The work I see done by DSPs and BTs is invaluable and should be promoted and supported by all as it gives people in the I/DD community the ability to have meaningful lives and to access the community that doesn't always know how to welcome them. We must all do our part to serve the underprivileged communities around us, especially when we look at disabilities.

Georgiana Provance, works for a service provider in a role other than direct support
Fayette Resources, Inc.
Connellsville, Pennsylvania

I have worked in this field for 17 years. Every single day, I see the impact of community-based services; on the people we support, on their families, and on the Direct Support Professionals (DSPs) who make this work possible.

Families: Finding Peace of Mind

One of the most constant fears I hear from families is: What will happen to my child when I'm no longer here to care for them?

I've sat with parents as they cried through that fear. It colors every moment of their lives.

The moment a family finally secures funding for Home and Community-Based Services (HCBS), I watch that fear start to ease. As their child transitions into a community setting, with a provider they trust, they begin to find peace. They see their child living safely, engaging in meaningful activities, building relationships, and having a life of their own. That relief is the impact HCBS has on families: the knowledge that their loved one will be okay.

People Receiving Services: Safety, Stability, and Belonging

HCBS services transform lives. I've seen people who have no family involvement find a true sense of belonging. I've seen people leave their childhood homes and discover independence, new interests, and friendships. And our organization is known statewide for transitioning people out of hospital settings, people who have been told they are "too complex," and helping them thrive in the community through a person-centered approach focused on safety, health, and happiness.

Direct Support Professionals: Quiet Heroes of Community Inclusion

Finally, I witness every day the extraordinary work of DSPs. Their job could fill a novel. They support people through every aspect of daily life: meal prep, medication, transportation, grocery shopping, personal care, community participation, and so much more. They even support people who have feeding tubes or require assistance with bathing and mobility. But they also support the small, human moments that define a life.

DSPs are the ones who:

Sit beside a hospital bed, holding someone's hand as they pass away.

Throw birthday parties and create holiday traditions for people who have no family.

Learn how to use feeding tubes, manage choking risks, or adapt care as someone ages.

Return to work after being physically harmed during a behavioral crisis because they understand that behavior is communication.

Set up speakers and lighting so a deaf individual can feel his favorite music, sparking dance parties that filled the house with joy.

Teach, share, and celebrate hobbies, like the DSP who helped a person catch a fish so memorable it now hangs mounted on a wall.

Attend trainings to support someone through their first romantic relationship, helping them experience love safely and confidently.

These are not isolated stories. They are the everyday reality of DSPs. This work is both essential and deeply human.

HCBS Is Not Optional, it's a Lifeline

HCBS allows people with disabilities to live in their communities, build relationships, pursue joy, and contribute meaningfully to the life of their neighborhoods and towns. It provides families with peace of mind and ensures people are not forced into institutions or hospital settings that limit their autonomy.

HCBS isn't just vital to individuals or families, it strengthens the fabric of our communities. Everyone deserves the opportunity to create a life they choose. HCBS makes that possible.

Tammy Roche, works for a service provider in a role other than direct support
Ellen Siciliano's Story
Barber National Institute
Erie, Pennsylvania



When picturing an older adult who is truly active in their community, Ellen Siciliano stands out. Her life is a vibrant tapestry of experiences and connections, thanks to her involvement in programs and activities that keep her engaged and fulfilled.

Ellen participates in Special Olympics, Theatre of the Arts, and even ice skating competitions. She contributes as part of a cleaning staff, enjoys "Time of Your Life" vacations, attends camps, and travels for family functions out of state. These activities are more than hobbies; they are opportunities for Ellen to connect, grow, and thrive.

Before joining Barber National Institute and engaging in these programs, Ellen's life was far less involved in the community. In fact, her desire for more meaningful engagement was one of the reasons she left her previous provider. Without these opportunities, Ellen would not feel as fulfilled or happy as she does today.

The impact of these activities is profound. Ellen has found purpose and built lasting relationships. Anywhere she goes, she knows someone from her activities—a clear sign that she is truly part of her community. This sense of belonging is invaluable.

However, when community-based services are limited or unavailable, individuals like Ellen face isolation. For those who crave connection, the

absence of these programs can lead to loneliness and frustration, forcing staff to think creatively to meet these needs.

Programs that promote community participation do more than fill time, they empower individuals to choose activities they love and foster a sense of connection that institutional settings often cannot provide. In these programs, people are not just residents; they are active participants in life.

Ellen's story reminds us that community engagement is essential for quality of life. It's about more than activities. It's about dignity, purpose, and belonging.

About Barber National Institute

Barber National Institute is guided by compassion, innovation, and an unshakable belief in human potential. We work every day to help make dreams come true for people of all abilities. Founded in 1952 by Dr. Gertrude A. Barber, we have grown from a single classroom into a comprehensive network of services for 5,400 adults and children with intellectual disabilities, autism, and behavioral health challenges. With locations in Bedford, Erie, Pittsburgh, Philadelphia, Somerset, and Warren, we empower individuals and families through education, residential options, employment, and community programs. We carry forward Dr. Barber's legacy and vision of a world where everyone belongs and lives to their fullest potential.

Tammy Roche, works for a service provider in a role other than direct support
Diane Carpenter's Story
Barber National Institute
Erie, Pennsylvania



When we think of an older adult who is active in their community, Diane Carpenter immediately comes to mind. Diane is a vibrant example of how staying engaged can transform lives. She loves going out to eat, shopping, taking trips, staying in hotels, and even camping. These activities keep her connected to the world around her and bring joy to her everyday life.

Before embracing these experiences, Diane's life was much quieter—she typically stayed at home and watched TV. Without these opportunities, her mobility would have declined, depression could have set in, and negative behaviors might have emerged.

Instead, Diane now thrives. She enjoys ordering her own meals at restaurants, picking out clothes, smiling at strangers, and meeting new people. These simple yet meaningful interactions give her a sense of independence and happiness.

Unfortunately, when community-based services are limited or unavailable, individuals risk losing the ability to express themselves, discover new interests, and learn new things. Programs that promote community participation are essential because they offer experiences that institutional settings often cannot. In facilities with large populations and minimal staff, people can feel confined, like living behind four walls with little chance to see the outside world. Imagine never experiencing fresh air, sunsets, or new scenery; it would feel isolating and hopeless.

Community engagement isn't just about activities; it's about dignity, joy, and quality of life. Diane's story reminds us that these programs are not luxuries; they are lifelines that keep people connected, active, and fulfilled.

About Barber National Institute

Barber National Institute is guided by compassion, innovation, and an unshakable belief in human potential. We work every day to help make dreams come true for people of all abilities. Founded in 1952 by Dr. Gertrude A. Barber, we have grown from a single classroom into a comprehensive network of services for 5,400 adults and children with intellectual disabilities, autism, and behavioral health challenges. With locations in Bedford, Erie, Pittsburgh, Philadelphia, Somerset, and Warren, we empower individuals and families through education, residential options, employment, and community programs. We carry forward Dr. Barber's legacy and vision of a world where everyone belongs and lives to their fullest potential.

Tony White, a direct support professional
Danville, Virginia

My name is Tony White, and I am a caregiver for an individual with several health-related problems. The individual, whose initials are JW, has been living with me for the past seven years. Given that he was born with these challenges, JW's issues surpass those of most individuals. Any reduction in funding or benefits would be devastating for him.

His goal in life is to live as normally as possible, and he fights daily to function. JW is not only a fighter but also an optimist about the future. He stays busy encouraging others who have needs and challenges. His dedication to overcoming his disabilities is remarkable. A decision to reduce funding or disqualify him from benefits would not only impact JW but also affect many seniors who have worked their entire lives to retire with dignity and respect.

Please consider the individuals who have fought for normalcy in life. Some individuals discover it effortless, while others encounter unexpected challenges. By the grace of God, they are still here. I urge you to think carefully before making any final decisions regarding health coverage for individuals with aging and disabilities. I pray that your hearts will be touched, your minds will reflect, and your votes will oppose any reductions in health coverage or disqualifications for individuals with disabilities. Thank you, and may God bless you.

Alison Armstrong, a direct support professional
EnCircle
Roanoke, Virginia

I am a DSP to a wonderful man named Hunter. He loves to make jokes and spread smiles everywhere he goes. He is active, bright, and kind. He likes to walk on the Greenway and enjoy the natural beauty that his community has to offer. He frequents a local greenhouse and often admires the plants and flowers there. He is friendly with the staff and is always warmly welcomed. He worked hard to sit quietly and calmly for hours in a movie theater and now has a favorite local theater he likes to support. He helps to grocery shop and likes doing chores and errands for his Nana.

Hunter is able to engage with his community and help others because of I/DD services that allow him to continue his education and practice crucial life skills and activities of daily living. Without these services, we deny the community access to Hunter as much as we are denying Hunter access to his community. It is a disservice to all of us to exclude and alienate these important community members that have so much to give back.

Lindsey Rasmussen, a person who receives I/DD services
Hope House Foundation
Virginia Beach, Virginia

Good morning, my name is Lindsey Rasmussen. I am a 27-year-old individual with developmental disabilities and have lived in my own apartment with support paid for by my Medicaid Waiver in the city of Virginia Beach for almost 2 years.

I am a very active person, who likes to stay on the go. I can do a lot on my own but occasionally I need staff assistance. Those times that I do need assistance, often its very limited on how long they can stay. I am a cat lover, and hope to get one of my own soon. I eat healthily and exercise regularly so that I live a long and productive life.

I am proud of advocating for myself and others. I have a lot to say on many issues. Since I have been living on my own, I have gained a wealth of independence, It has taught me to be aware of my surroundings and how to stay safe from harm, which used to be my parents job. I want others with disabilities to share this independence that I have by living in their own apartment. What a feeling…

Allison Whittaker, parent of a person who receives I/DD services
Reva, Virginia

Hello,

My name is Allison Whittaker. I am the aging 61 year old single mother of an adult son with down syndrome. My son David Rogers is currently 38 yrs old and has lived his entire life at home with me. I was 22 years old when he was born at that time I was the second youngest mother in US to give birth to a child with this condition. So we have seen many changes in this time.

Currently David attends a community based day support program called DIDLAKE which is an amazing support program. The staff and clients at this program are an amazing group of caring & supportive individuals that have become family and are always there if needed.

The program director Mr. Antwan Bland is one of the most amazing humans I have ever met and was trained by Ms. Jackie Thompson Walker both of these are my ROCKS, my ANCHOR & Angels that get me thru every day now with my own medical diagnosis of lupus.

This program and programs like it are vital to parents like me in keeping a routine and being a productive part of our society.

The other day while driving him to his support program I observed my son at a stop light. Dancing in his seat and air guitar going to music playing in the truck next to us. The driver noticed him and began to mimic him and they smiled, laughed and had a moment of true happiness together. I suddenly noticed the lady in the car to my left who watched this beautiful event take places and we all waved and felt the presence of community.

Without programs like these individuals and there families will suffer greatly.

These individuals can speak volumes without words to communities everywhere.

Our society depends on this program & others like it.

It is only me and my son depending on you and others to stand strong and keep building programs like this to ensure our most precious gifts from God thrive .

Thank you,

Ally Whittaker

Betty V. Snapp, grandparent of a person who receives I/DD services
Stephens City, Virginia

In January, 2022, my 42-year old granddaughter, Elizabeth, came to live with me, after living in North Carolina for 22 years with her mother and step father. They were both terminally ill, and she needed care. My husband had died a year earlier, and we were a blessing to each other.

With Down Syndrome, Elizabeth had a Medicare account but her NC Medicaid was, of course, invalid in VA. Through the help and guidance of her amazing Case Manager at Northwestern Community Services Board, she received her Virginia Medicaid and DMAS. This has given her the security of excellent medical care and day programs (NWWorks and others).

In February, 2025, she moved to an enCircle residence in Frederick County - again through the assistance from the above services, and it is comforting to know she is well cared for in a home-like environment. She is also working toward employment and independent living at some future time.

Jennifer Mathews, a direct support professional
Encircle
Galax, Virginia

I have been working with people with ID for going on 18 years. I have got to witness 3 of the people I have cared for over this time see the ocean for the first time. I have travel many states and shared many adventures with all the people that I have had the pleasure of working with. Just to get to be a part of someone's life and experience great things with the individuals I have worked with has been a blessing. I hope and pray I can continue in this line of work as long as my body and mind seem fit to. We have very good Day support programs as well that helps with giving me time to clean and shop for the house hold. Not sure what would happen to all these great people if funding were to stop.

Elvira Goldschmidt, a person who receives I/DD services
Hope House Foundation
Norfolk, Virginia

I am a person with developmental disabilities, and for the past 11 years I've lived in my own apartment in Norfolk, with the support provided by my Medicaid waiver. I'm here today to talk about the independence I have been able to have. I have a job I enjoy, a dog named Roscoe, and I'm in a happy relationship. My job means a lot to me because I get to meet new people, make new friends, and feel valued for my hard work. It has helped me grow and become the person I am today. Having the right supports in my own home help make it all possible. Everyone deserves the right to live in their own home, with the help they need, to live a life like yours.

Sandra Phillips, parent of a person who receives I/DD services and a direct support professional
Encircle
Salem, Virginia

I am my son's keeper. I have watched over him for 44 years. I watched over my two daughters too, but they were able at Somerville enjoys and point to take over their own care. My son cannot. I have advocated for him and keep his best interests foremost in his care. My son has autism and cerebral palsy and some some delays in his cognitive abilities.

His choice is to live at home with me. It is a 24/7 job. We have been fortunate to find day support at Encircle. He loves it. He has friends. He goes out into the community. He has crafts he does, goes to movies, goes bowling, all things he enjoys and that enrich his life and provide a more normal life for him. There are many things he cannot do, but there are many that he can. He is very social and loves meeting new people. " What's your name.?" He asks and then he usually remembers. He has become more talkative. He understands more. He is even anticipating the needs of others.

He has come a long way. As a teen he was loud and yelled when out in public. It was difficult to take him places because of this. He has now made it possible to get out, experience new things, meet new people, expand his enjoyment of life.

We all want our children to be happy and successful and to have a good life. My son has that. It may not be what your child has but his accomplishments are monumental for him. Noticing that the paper towels are low and getting a new roll is a great hurdle for him to overcome, anticipating needs. I am proud of him. And he has a sense of worth. He likes to help. We discuss how we can help others. I make sure I compliment him on his good work and he is visibility proud of what he's done.

If we did not have his day support services or the support of caring for him in our home, his life would be quite different. When he was born, we lived in Richmond. Next door was a lady my age who had Downs Syndrome. We lived next door for 5 years. I never saw her outside of her house. She stayed in and wore her pajamas all the time. At that time I had no idea that my infant would have a disability. When I found out, I was determined not to isolate my child. And, as difficult as it has been at times, without the help of services provide through agencies like Encircle, services that are funded by Medicaid waiver. If we lose this service, we both will lose our quality of life. He loses his freedom of choice. My being able to work one on one with him has enhanced his opportunities for more " normal life".

Chantal M. Bokassa, a direct support professional
Encircle Agency
Culpeper, Virginia

In 2013, I began working with intellectual and developmental disability services. I did not know the impact my life was going to have for the better. The training and the knowledge gained to become a direct support professional was great because I was going to make a life changing impact on those I was going to interact with and to care for. Imagine calling 911 to save the life of an ID individual in your care for low oxygen level in order to safe their life

It is such a great feeling to know that you made a difference in someone effected with intellectual and developmental disability with your smile or with your kindness or with your generosity or with your effort or with your time and with your love. A life of servicing intellectual and developmental people in your community is fulfilling.

I leaned not to take things in life for granted. I learned to love and to appreciate those I am carrying for and interacting with. I leaned that we all need love and happiness and to care for someone else besides myself. I leaned not to be selfish. I dedicated my life to serve others and that is what I do daily as a direct support professional in my community. The ID population needs us, and we need them in order to help one another.

U.S. Senate Special Committee on Aging
Aging in Place: The Impact of Community During the Holidays
Wednesday, December 3, 2025

The American Network of Community Options and Resources (ANCOR) appreciates the opportunity to submit a statement for this hearing, *Aging in Place: The Impact of Community During the Holidays*. We appreciate this committee's focus on the importance of community living and urge the committee to support policies to invest in and strengthen community-based services for people with intellectual and developmental disabilities (I/DD).

Founded 55 years ago, ANCOR is a national, nonprofit association representing more than 2,500 private, mostly non-profit community providers of long-term supports and services to people with I/DD, as well as nearly 60 state provider associations. Combined, our members support more than one million individuals with I/DD in all 50 states across their lifespan and are funded almost exclusively by Medicaid. Our mission is to advance the ability of our members to support people with I/DD to fully participate in their communities.

Community-Based Services Benefit Individuals with I/DD

Medicaid-funded community-based services are a lifeline for people with disabilities. ANCOR's members offer a broad range of supports to help people with I/DD live full and independent lives in their homes and communities. Through Medicaid-funded community-based services, people with I/DD have access to a spectrum of person-centered supports, including assistance with activities of daily living, skill-building supports, community integration, and employment opportunities. These supports enable people with I/DD to develop a greater level of independence and autonomy and contribute meaningfully to their communities.

Community-based services also honor individuals' and their families' choices for those who choose to remain in their homes and communities, rather than large institutional settings. Moreover, there is abundant empirical evidence that people with I/DD lead happier, healthier, and more productive lives in community-based settings with opportunities to make choices about their lives. This research indicates that:

- People who move from state-operated public institutions to smaller community homes are happier, healthier, have more control over their lives, and are better able to function more

independently after they move.[1]

- Individuals moving from large institutions to community settings consistently develop their daily living skills to a higher level than their peers who remain institutionalized.[2]
- People with disabilities have more opportunities to exercise choice over their lives when residing in community settings and such opportunities are associated with positive outcomes and a higher quality of life.[3]

Community inclusion—the ability to live and engage in the community just like everyone else—leads to improvements in a person's overall health and well-being. Unfortunately, individuals with disabilities are twice as likely as other populations to experience social isolation and loneliness.[4] This only underscores the importance of supporting community-based services. For more on the importance of community-based services, see Stories Collected from ANCOR's Provider Network.

Community-Based Services Benefit Families, Communities, and Local Economies

In addition to improving individuals' health and well-being, Medicaid-funded community-based services enable individuals with I/DD to receive support outside of family caregivers. Providing support options for people with disabilities enables family caregivers to remain in the workforce and continue to earn wages. Without the option to maintain employment, family members lose thousands of dollars annually in unearned wages[5] and face mounting out-of-pocket expenses and the physical and emotional strain of caregiving, leading family caregivers to be more likely to need additional support through public assistance.

These services benefit communities in a myriad of ways. Community providers of I/DD services support a robust economy as employers of one of the fastest growing workforces, as well as providers of employment support services for people with disabilities. The direct impact of employing thousands of individuals as direct support professionals as well as the indirect impact of those employees' economic output in their local communities produces positive outcomes at the state level. For example, a recent study of New York state disability services found that the economic impact was double the investment the state disability agency made into those services—an investment of $6.7 billion into disability service providers led to $14.3 billion in economic activity.[6]

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[1] Sheryl Larson et al., *Behavioral Outcomes of Moving from Institutional to Community Living for People with Intellectual and Developmental Disabilities: U.S. Studies from 1977 to 2010*, Research and Practice for Persons with Severe Disabilities (2013), *available at* https://journals.sagepub.com/doi/10.2511/027494813805327287.

[2] National Association of State Directors of Developmental Disability Services & Association of University Centers on Disabilities, *The Effects of Community vs. Institutional Living on the Daily Living Skills of Persons with Developmental Disabilities* (2011), *available at* http://www.evidence-basedpolicy.org/docs/evidence-based_policy.pdf.

[3] Katherine M. Burke et al., *Self-Determination Research: Current and Future Directions*, Behavioral Sciences (2024), *available at* https://doi.org/10.3390/bs14070613

[4] Glenda M. Bishop et al., *Disability-Related Inequalities in the Prevalence of Loneliness Across the Lifespan: Trends from Australia, 2003 to 2020,* BMC Public Health (2024), *available at* https://doi.org/10.1186/s12889-024-17936-w.

[5] *Families Caring for an Aging America*, National Academy of Sciences (2016), https://www.ncbi.nlm.nih.gov/books/NBK396402/.

[6] Laura Schultz, *The Role of Disability Service Providers in the New York State Economy* (2021), *available at* https://rockinst.org/wp-content/uploads/2021/12/the-role-of-disability-service-providers-in-the-new-york-state-

Additionally, community providers support individuals with disabilities to gain and retain employment through job coaching and employment supports to help them enter and stay in the workforce. And in doing so, help individuals with I/DD gain further independence through employment, better enabling them to contribute economically to their communities.

Medicaid home and community-based services are also a cost-efficient solution as compared to the alternative of providing long-term supports in a nursing facility or large state-run institution. Medicaid home- and community-based services are far less costly for states than long-term services and supports rendered in institutional settings. The average annual per capita cost to serve someone with I/DD though a home and community-based waiver program is $49,764 while the projected cost to serve that individual within a large state-run institution would be $325,580[7] and the average per capita cost to support someone with a mandatory service, such as in a nursing facility, is $111,325.[8] Investing in community-based supports also enables states to ensure individuals receive the supports they need and can avoid more costly services like hospital or emergency care services down the line.

Congressional Support Is Necessary to Ensure the Sustainability of Community-Based Services

Even with data supporting the need for community-based services for people with I/DD, these services are in a fragile state. ANCOR recently conducted its sixth-annual survey of community providers, and the findings indicate that 88% of providers report experiencing moderate or severe staffing challenges in the past year, resulting in 62% of providers turning away new referrals and 52% of providers considering further cuts to programs.[9] Now, providers are concerned about the impact of recently passed legislation that places limitations on state and federal funding for Medicaid and how it might further exacerbate the already fragile state of Medicaid community-based services and lead to decreased access to services.

Across the country, more than 500,000 people with I/DD are already on states' waiting lists for home- and community-based services.[10] Wait times are often several years to decades long, forcing people with disabilities to either go without the support they need or be forced into hospital emergency rooms, nursing homes, and large high-cost state-run institutions. Service reductions resulting from the ongoing workforce shortage and pending Medicaid cuts will only grow these years-long waiting lists, putting community supports for people with disabilities out of reach for thousands of families, and

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economy.pdf.

[7] Residential Information Systems Project, *In-Home and Residential Long-Term Supports and Services for Persons with Intellectual or Developmental Disabilities* (2020), *available at* https://icis.umn.edu/files/a6fkEiad6J/2020_risp_report?preferredLocale=en-US.

[8] American Council on Aging, *2024 Nursing Home Costs by State and Region* (2025), https://www.medicaidplanningassistance.org/nursing-home-costs/.

[9] American Network of Community Options and Resources, *The State of America's Direct Support Workforce Crisis 2025*, https://www.ancor.org/wp-content/uploads/2025/10/The-State-of-Americas-Direct-Support-Workforce-Crisis-2025.pdf.

[10] Kaiser Family Foundation, *Number of People Waiting for Medicaid Home Care (HCBS), by Target Population and Whether States Screen for Eligibility* (2024), kff.org/medicaid/state-indicator/number-of-people-waiting-for-hcbs-by-target-population-and-whether-states-screen-for-eligibility/.

raising unnecessary costs for states to cover health care in more expensive settings.

To ensure a sustainable system and keep the promise of community living for people with I/DD a reality, Congress must support and invest in community-based services. The data is clear that increased federal investments help to strengthen and sustain community-based services. Recently, temporary federal investments into the Medicaid Home and Community-Based Services (HCBS) program were authorized through the American Resue Plan Act (ARPA). This funding was instrumental for states in strengthening their community-based services, with every state and the District of Columbia utilizing ARPA funding to invest in strengthening their direct support workforce. ANCOR's annual provider survey demonstrates that during this time period, even though community-based providers continued to experience workforce staffing shortfalls, fewer providers indicated they were closing programs or services.[11] For example, in 2022, 63% of survey respondents reported closing programs or services. After the release of additional federal funding through ARPA, that figure dropped to 44% in 2023, decreasing to 39% in 2024, and down to 29% in 2025.[12]

Congressional support for legislation that will bolster community-based services is necessary for the sustainability of these services. We ask for support for the HCBS Relief Act (S. 2076), which would provide an enhanced federal match for states to invest in their Medicaid Home and Community Based Services programs. We also urge support for the Recognizing the Role of Direct Support Professionals Act (S.3211), which would help create a standard occupational classification for direct support professionals, enabling accurate data collection on the direct support workforce.

Our communities are at their best when all people, including people with disabilities, have the opportunity to develop skills, achieve greater independence, and successfully reach their goals. Sufficient Medicaid funding and a robust community provider network are foundational to building a stronger America for everyone. The best way to keep health care affordable, sustainable, and available for the individuals with I/DD who depend on it is to invest in community-based services.

For questions or more information, please reach out to Elise Aguilar, Senior Director of Federal Relations, at eaguilar@ancor.org.

Sincerely,

Barbara Merrill
Chief Executive Officer ANCOR

[11] American Network of Community Options and Resources, *The State of America's Direct Support Workforce Crisis 2025*, https://www.ancor.org/wp-content/uploads/2025/10/The-State-of-Americas-Direct-Support-Workforce-Crisis-2025.pdf.
[12] *Id.*

From: Maria Faralli
To: HCBS (Aging)
Subject: Arc contributions to community in Cape May County N.J.
Date: Wednesday, November 19, 2025 3:04:51 PM

Our ARC is an a integral part of community with our Special needs adults.
My daughter is a major benefactor of all the Special Services they offer.
First of all, the staff is exceptional,headed by a brilliant women, Majken Mechling.
My sweet daughter lives at home but we participate in all the outings the ARC offers. We have went to the Eagles training camp and Phillies baseball game, just to name a few.
They also have monthly dances.
We just had a beautiful Thanksgiving feast too.
We love our ARC!!

Yahoo Mail: Search, Organize, Conquer

Center for Public Representation

Statement for the Congressional Record from

Center for Public Representation

Submitted to
The Special Committee on Aging
United States Senate

Hearing on "Aging in Place: The Impact of Community During the Holidays"

December 3, 2025

The Center for Public Representation (CPR) thanks the Senate Special Committee on Aging for holding this hearing about the importance of community living for older adults and people with disabilities. We also appreciate your call for stories about the importance of programs – like Home and Community Based Services ("HCBS") Medicaid Waiver Programs, Centers for Independent Living (CILs), and other services and supports – that allow people with disabilities and older adults to participate in their communities, given their federal funding and coordinated administration are currently under attack.

CPR is a national legal advocacy center that has been promoting community integration and agency of people with disabilities, including older adults, for nearly fifty years. CPR's major activities include enforcing the rights of institutionalized and previously institutionalized people with disabilities; designing and implementing innovative systemic reform initiatives with and for people with disabilities; and serving as a state and national training, technical assistance, and support center. CPR uses legal strategies, reform initiatives, policy advocacy, partnerships, and training to address our systemic priorities, including promoting community living for people with disabilities of all ages.

Most older adults and people with disabilities want to live in their own homes and communities, rather than nursing facilities or other institutions. With appropriate supports, people are generally happier and healthier in the community.[1] People's community life is not limited to only where they live, but also where they work and spend their days. People with disabilities want to work, and more than half a century of research and demonstration have found they can

[1] ADMINISTRATION FOR COMMUNITY LIVING, *About Community Living* (last modified on Sept. 19, 2025), https://acl.gov/about-community-living.

do so, if they are supported with individualized supports, technology, and positive expectations.[2] The integration mandate of the Americans with Disabilities Act has been found to not only apply to residential settings,[3] but also employment ones.[4] For States and service systems to meet this mandate, the funding of robust community supports and services, including HCBS and federal Rehabilitation Act funded-services, is critical.

CPR has led legal initiatives throughout the country to promote community integration for people with disabilities, redesign service systems to facilitate community inclusion and choice, promote access to HCBS, and expand collaboration with people with lived experience. We have been part of cases that resulted in the closure of almost twenty-five public institutions for people with disabilities in ten states and the transition of the residents of those facilities to integrated community settings.[5] Because of our work, tens of thousands of children now receive support in their own homes and communities[6] and thousands of people have transitioned out of psychiatric, developmental disability, and nursing institutions to live and receive services in the community.[7] And thousands of individuals in sheltered work and youth with intellectual and developmental disabilities leaving public schools have accessed paths to integrated employment.[8]

CPR has seen the first-hand the impact that community-based services have on the lives of people with disabilities. That impact is best illustrated by people's own stories. With that in mind, we wanted to highlight the lived experience of two people who benefited from CPR's "Bringing People Home" initiative.[9] This initiative is focused on improving access to community living by implementing a Massachusetts settlement in the first cross-disability case mandating community alternatives for people with disabilities, including older adults, who are unnecessarily institutionalized in nursing facilities.[10]

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[2] Ruby Moore & Steven Schwartz, *Advancing Competitive Integrated Employment through Legal Advocacy* Systems, Disability Employment Technical Assistance Center-2021-P&A-2, at 3-5 (Sept. 2021), https://www.centerforpublicrep.org/wp-content/uploads/DETAC-2021-PA-2_Final_508-1.pdf.
[3] *See Olmstead v. L. C.*, 527 U.S. 581 (1999).
[4] *Lane v. Kitzhaber*, 841 F.Supp.2d 1199, 1205 (D. Or. 2012).
[5] *See* CENTER FOR PUBLIC REPRESENTATION, *Community Integration Litigation,* https://www.centerforpublicrep.org/issue/community-integration/litigation/ (last visited Dec. 5, 2025).
[6] For example, CPR secured a federal court holding that Medicaid-eligible youth with serious emotional disturbance have a right to home-based treatment (https://www.centerforpublicrep.org/court_case/rosie-d-v-romney/) and is leading a pending case in Georgia that was brought on behalf of 3,500 students with behavioral disabilities in segregated education in violation of the ADA, Section 504 of the Rehabilitation Act. and 14th Amendment of the U.S. Constitution (https://www.centerforpublicrep.org/court_case/gao-v-georgia/).
[7] In Massachusetts, CPR led the first cross-disability case mandating community alternatives for thousands of people with disabilities unnecessarily institutionalized in nursing facilities (https://www.centerforpublicrep.org/court_case/marsters-et-al-v-healey-et-al/), as well as the first to establish the rights of nursing facility residents with intellectual and developmental disabilities to active treatment and community placement (https://www.centerforpublicrep.org/court_case/rolland-v-cellucci/); and to transition thousands of people with brain injuries from nursing facilities to integrated community settings (https://www.centerforpublicrep.org/court_case/hutchinson-v-patrick/).
[8] CPR successfully challenged sheltered workshops as a violation of the Americans with Disabilities Act, which resulted in a landmark settlement in Oregon (https://www.centerforpublicrep.org/court_case/lane-v-brown/).
[9] *See* CENTER FOR PUBLIC REPRESENTATION, *Bringing People Home*: *Marsters, et al. v. Healy, et al. Settlement Webpage,* https://marsters.centerforpublicrep.org/ (2025).
[10] *See* CENTER FOR PUBLIC REPRESENTATION, *Marsters, et al v. Healy, et al.* (D. Mass. 2022), https://www.centerforpublicrep.org/court_case/marsters-et-al-v-healey-et-al/ (last visited Dec. 5, 2025).



For almost three years, Sheri Currin languished in a nursing facility in Marlborough, Massachusetts – away from family and friends. While living there, she spent most of her time in bed, heavily medicated, and isolated. Through CPR's "Bringing People Home" initiative, Sheri finally had the chance to reclaim her life. With support from the MassHealth Moving Forward Plan Residential Supports (MFP-RS) HCBS waiver program, she transitioned from the nursing facility into a real home in Southborough.

The change has been transformative. In the community, Sheri is prescribed far less medication, is physically stronger, and no longer needs a Hoyer lift for transfers. She has her own private bedroom – decorated with her chosen furnishings, family photos, and the belongings that make the space truly hers. With assistance, Sheri moves through the home's spacious common areas in her wheelchair, spending time with her four housemates and relaxing on the outdoor patio.

Sheri is once again participating in the daily rhythms of community life. She helps with cleaning and laundry, and her greatest joy is being able to cook for herself in the kitchen – something she missed during her years in the nursing facility. She shops in the community, goes to the library, and visits her boyfriend. At the rehabilitation center she attends three times a week, she especially looks forward to spa days, where she can get manicures, pedicures, and massages. Most importantly, Sheri has her voice back. She describes her years in the nursing facility as feeling like she was in a coma – hearing the world around her but feeling invisible within it. Today, that has changed. "Nobody listened to me," Sheri says. "Now I have a voice and am heard."

Richard Caouette, a U.S. Army veteran, also was able to finally return to the community because of this initiative. After a stroke in 2020, Richard spent five long years in a nursing facility in Worcester, Massachusetts. He shared a small room with little natural light and endured long stretches of unstructured time with nowhere to go and nothing meaningful to do. Most days were reduced to walking the hallways, watching television, or sleeping – always under facility rules that left him feeling stripped of autonomy. As Richard says, "For me, living in a nursing home is like living under martial law."



That changed in July 2025. Approved for the MFP-RS waiver program, Richard moved into his new home in Northborough. Today, Richard is rebuilding a life that feels more like his own. He enjoys the privacy of his own bedroom and the dignity of contributing to household tasks. And for the first time in years, he gets to plan what his meals will be – a right he loves and one others take for granted. Perhaps most meaningfully, Richard has found community. "We have fun," he says of his housemates, with whom he plays games and watches sports. He also likes going out to shop for new clothes and items to personalize his bedroom. No longer needing to shout or pull a cord for help, Richard says of his new home, "It's way better. I'm glad I'm here."

Through the MFP-RS HCBS waiver, people like Sheri and Richard can access community-based supports, including assisted living and residential habilitation services; assistive technology; day supports and services, behavioral health support and navigation; home accessibility adaptations; peer support; physical, occupational, and speech therapy; supported employment, and transportation services, among others. This waiver is but one example of the HCBS programs that are vital community lifelines for people with disabilities and older adults and that are more cost-effective than institutionalization.

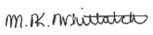
Over the last fifty years, critical inroads that have been made in promoting community integration and living for people with disabilities, including older adults. Maintaining and continuing to expand HCBS is essential to support people to remain in their communities and age in place, particularly in light of the growing demand and need. Yet steep cuts to federal Medicaid funding to States puts "optional" Medicaid services, like HCBS programs, on the chopping block. Faced with budget shortages in the past, States have repeatedly cut community-based services.[11] This trajectory risks reversing decades of federal policies and legislative efforts that have helped states shift Medicaid funding toward more integrated settings, as well the hard-one civil rights of people with disabilities.

We appreciate the opportunity to provide the Committee with our perspective on the importance of funding to support community living for people with disabilities and older adults. We look forward to continuing to serve as a resource to you in your important work.

Respectfully Submitted



Cathy E. Costanzo
Executive Director



Morgan K. Whitlatch
Senior Attorney

[11] Jessica Schubel *et al.*, *History Repeats? Faced With Medicaid Cuts, States Reduced Support For Older Adults And Disabled People*, HEALTH AFFAIRS (Apr. 16, 2025), https://www.healthaffairs.org/content/forefront/history-repeats-faced-medicaid-cuts-states-reduced-support-older-adults-and-disabled.

1090

Dear Senator,

I am writing to you as a homecare provider and a concerned citizen regarding the recent changes in healthcare regulations that directly impact home care services in our community. I am the Human Resources Manager at Convergence Home Care Services, a home care agency that has proudly served individuals and families in Madison County for six years.

The new policy changes have created barriers that are affecting both caregivers and the individuals who depend on home care to remain safely in their homes. Reduced reimbursement rates, increased administrative requirements, and delayed payment processes are threatening the stability of agencies like ours, and, in turn, putting vulnerable seniors and medically fragile individuals at risk.

Despite these changes, our company continues to provide essential care—often without billing or receiving reimbursement—because our clients' well-being is our priority. We routinely go above and beyond standard care duties. This includes helping clients with housing assistance, locating shelter resources, coordinating food support, and ensuring they have access to basic household necessities. These are services that fall outside traditional healthcare reimbursement, yet they are critical to keeping families safe, healthy, and stable.

Home care agencies are doing this work quietly and consistently, absorbing costs that larger healthcare systems would bill for but that community-level providers are simply expected to manage. Without legislative attention and support, many agencies will be forced to cut staffing, turn away clients, or close entirely—leaving thousands without essential services.

I respectfully urge you to consider supporting legislative or regulatory action that would:

- Expand slot capacity under the Pathways and Health & Wellness waivers so more of the estimated 123,000 Hoosiers in need can access services.
- Allow flexibility so family or legally responsible individuals can serve as paid caregivers—especially where non-family caregivers are unavailable.
- Recognize and support non-medical but essential services (housing assistance, food security, community resource coordination) as integral components of home care.
- Ensure reimbursement rates and administrative requirements do not undermine small and community-based home care providers, who serve rural and underserved populations.

- Address workforce shortages by investing in caregiver recruitment, training, and retention to meet the rising demand for home- and community-based services. (Added missing bullet formatting for consistency.)

Our sector—small, community-focused home care agencies—plays a vital role in helping vulnerable Hoosiers age in place, avoid costly institutionalization, and maintain dignity and independence. We stand ready to work with your office to provide concrete examples on how current policies play out in real homes and across Indiana.

Thank you for your attention to this urgent issue and for any support you can lend in protecting access to home care for Indiana's seniors and disabled residents.

Sincerely,

Donna Townsend

Human Resources Manager

Convergence Home Care Services

1092

Dear Senator,

The following situations represent real examples from clients our agency has served or is currently serving under Indiana Medicaid waivers. While the names have been changed to protect privacy, the circumstances are true and demonstrate the direct impact that recent policy changes and reimbursement issues have had on Hoosier families.

“Pam” — a 63-year-old senior placed on a waiting list after waiver changes

Pam is a single woman living alone in Indiana with Parkinson’s disease and significant mobility limitations. Prior to the recent policy changes, she received crucial support through the Aged & Disabled Waiver, including attendant care and home- and community-based services.

Following a short stay in a rehabilitation facility, she was unexpectedly removed from the waiver program and has not yet been reinstated. She is now at home without the necessary authorized services. Our agency has stepped in to provide essential support at no cost, including safety monitoring, basic care tasks, and ensuring food remains available in the home. Her family does what they can, but they cannot meet her needs alone.

Without these visits, Pam would almost certainly be forced into a nursing facility—a placement that goes against her wishes and could have been avoided with continued waiver support.

Our agency continues to provide these services because failing to act would cause immediate harm. However, this level of uncompensated care is not sustainable. Without legislative attention and action, vulnerable Hoosiers like Pam will continue to fall through the cracks of the system.

Thank you for your time and for your consideration of the serious challenges facing Indiana’s seniors.

Sincerely,

Donna Townsend

Convergence Home Care Services

1093

Dear Senator,

The following situations represent real examples from clients our agency has served or is currently serving under Indiana Medicaid waivers. While names have been changed to protect privacy, these circumstances are true and demonstrate the direct impact that recent policy changes and reimbursement challenges have had on Hoosier families.

“Rick” — an amputee displaced into homelessness due to lack of financial resources

Rick is an adult amputee who found himself living on the streets because he lacked the financial means to secure safe and stable housing. Without proper shelter, he faced significant health and safety risks.

Our agency stepped in to assist Rick by first arranging temporary lodging in a hotel and ensuring he had access to food, hygiene supplies, and other essential necessities. We continued working with him until we were able to help secure an apartment, providing him the stability and dignity every Hoosier deserves.

Our agency continues to provide these supports because failing to act would result in immediate harm. However, without legislative action, this level of uncompensated care is not sustainable. Vulnerable Hoosiers like Rick will continue to fall through the cracks unless meaningful change is implemented.

Sincerely,

Donna Townsend

Convergence Home Care Services

1094

Dear Senator,

My name is Dontay Jones, and I care for Mr. Myers, a man whose entire ability to live safely at home depends on the support he receives. When his authorized care hours were reduced, it wasn't just a policy change—it was a shift that immediately placed his health, safety, and independence at risk.

Mr. Myers didn't suddenly need less help. The only thing that changed was the system's willingness to give it. Without those hours, he now faces moments every day where he must choose between struggling alone or putting himself in danger. And when a small change in hours leads to a fall, a hospitalization, or a forced move into institutional care, everyone—taxpayers, the state, and families—ends up carrying a heavier burden.

This decision isn't about politics or budgets. It's about what happens to a real person when the support that keeps him steady is taken away. Restoring Mr. Myers hours would not cost the state nearly as much as the consequences of letting him go without the care he needs.

One choice from your office could give him back stability, safety, and dignity—things every person deserves, whether or not they have a voice strong enough to fight for themselves.

Thank you for considering how much this truly means.

Sincerely,
Dontay Jones
Convergence Home Care Services

Seniors with Disabilities: Caring for a Unique Population

Americans 60 and older living with an intellectual or developmental disability occupy a unique community within the I/DD and senior-care field, and one that remain largely overlooked by the current system.

Currently numbering an estimated 1.4 million adults—and set to grow in the coming decades—they deserve a unique set of facilities, programming, and consideration when creating plans for support. As Chief of Programs at CP Unlimited (CPU), an organization supporting adults with disabilities and others seeking housing, there are immediate and long-term strategies that can help providers like ours address the specific needs of this expanding population.

Presently, there are no facilities explicitly for older adults with disabilities and this must change. Nursing homes and sub-acute care settings need to be integrated into the landscape of offerings to address their complex medical and behavioral needs.

Further, the majority of existing facilities accommodating individuals with I/DD lack specialized staff training. Nurses and staff caring for seniors with autism, Down syndrome, cerebral palsy, and other disabilities require nuanced instruction and devoted time to support sensory issues, non-verbal communication including the use of devices like picture boards, and behavioral supports in a compassionate and skillful manner. Without this instruction, we run the risk of providing a lower quality of healthcare and deleterious outcomes for these seniors.

For seniors with disabilities living independently or in supported housing, a day program is a central part of their daily life and identity. Within these settings, the use of TEAMS for live classes and events and services like KIBU for on-demand lessons can have beneficial effects on mood and engagement, alongside in-person activities.

However, as they age, we find they grow less interested in the typical day program environment, which is fitting as the system is designed for a steady influx of younger participants as they age out of traditional school settings.

CPU recognized the growing need to support aging individuals in day program settings and responded by opening a senior division at the *Carmen Aquilone Day Program* in Brooklyn. While the initiative has shown mixed success, it highlights a critical and emerging challenge: Most existing day programs were originally created for lifelong participation rather than retirement. This means there is a gap in services for those experiencing the effects of aging, and therefore critical issues like physical and cognitive decline, dementia (particularly common among individuals with Down syndrome), mobility challenges,

sensory loss, and chronic health conditions that require adaptive supports, might not be fully addressed.

To meet these evolving needs, it will be up to I/DD agencies to develop innovative models within existing day programs, such as:

- Senior clusters or dedicated “retirement rooms” with slower-paced activities
- Community partnerships that provide meaningful engagement outside traditional program walls
- Intensive staff training on aging-related conditions, dementia care, and end-of-life planning

Parallel to the work of non-profits, more can be done at the local and state level. Senior programming, already minimal from city organizations, is barely non-existent for older adults with disabilities. Additional attention and offerings from arts and cultural institutions will help add to the list of choices. One small fix: adding a height-adjustable adult changing table in large public venues will make events more accessible for people with disabilities.

On the administrative side, deepened assistance with social security disability benefits would help make sure that this population struggles less, and greater outreach for Medicaid renewals can safeguard that people won’t fall through the cracks. Partnering with organizations like CP Unlimited are key in reaching this often-overlooked group.

For seniors with disabilities, life can frequently be challenging. By creating more focused, person-centered residential and program options, with investment from the state, we can close existing gaps and ensure quality of life for aging individuals with I/DD while respecting their changing interests and abilities.

The Importance of Community Living for People with Disabilities

I am a public-school educator and mother to a son with Autism. I am also a Board Member of The Arc Jefferson – St. Lawrence. My son is very dependent on Home and Community-Based Services (HCBS), to help support his development and independence. He has been receiving services since he was 8 years old. These programs allow him to accomplish his developmental and independence goals. My son did not learn to read in school, he did not learn math skills in school, he did not learn to talk in school. He learned those things through the direct 1:1 guidance provided to him through his support services.

My family and I are so thankful for the gains that my son has made because of the programming he has in the home and community. My son is unable to be left alone, and there are many obligations I am not able to bring him with me to attend. Without this support, I would not have been able to continue my work as a secondary school educator because I would be forced to quit my job in order to take the place of these services. I actually am not sure how I would be able to stay on top of my health, go to doctor appointments and screenings, and take care of my family without this service. I cannot imagine our lives without it.

Losing this programming would significantly diminish the quality of life for my family, especially my son. Families want to take care of their children with disabilities, including adult children with disabilities. We want them to become as independent as possible and thrive in our communities. However, we the care-takers, need support for our children in order to be able to accomplish this. HCBS programming allows people to thrive and we can fulfill our adult responsibilities and be functioning members of society, as well.

Cuts to HCBS programming for individuals with disabilities would be detrimental to lives of millions and would have a negative domino effect on other unanticipated areas of society. My son can read, he can write, he can talk, he can follow social rules, he can learn, he is happy and thriving and wants to be a contributor to his community, and that is in large part due to the support services he receives.

Wendy LaFave
315-767-0171
wendylafave@gmail.com



Dear Senator [Last Name],

I am writing to express my profound concern regarding the recent changes to Medicaid, particularly as they affect our senior citizens. The One Big Beautiful Bill Act has resulted in many older adults losing essential care. As someone who works in home care, I see firsthand the challenges our seniors face every day. Many who were once active, independent members of our community have now become fully reliant on limited support from their loved ones.

I would like to share the story of Thelma, age 78. Before her husband passed away, both of them received home care services through Medicaid. Her husband was battling cancer, and due to her own mobility limitations and health issues, she was unable to care for both him and herself. After his passing, her health began to decline rapidly.

Only a month later, she encountered complications with her Medicaid coverage. The frequent updates and policy changes became confusing and difficult for her to navigate. As a result, her home care services were discontinued. While she was trying to reapply, the implementation of the One Big Beautiful Bill Act created new barriers that made obtaining services even more difficult.

Thelma is a retired first lady of her church and is unable to work. Her family cares deeply for her, but due to economic pressures and work obligations, they can provide help only when they are able. Her greatest fear is that her health will continue to deteriorate simply because she cannot receive the assistance she desperately needs.

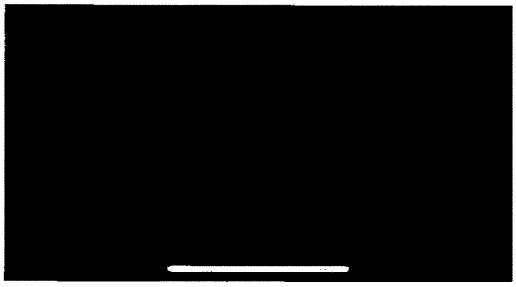
I respectfully urge you to reconsider how these policy changes impact those who cannot advocate for themselves—those who have spent their lives giving to their communities. Our seniors deserve dignity, stability, and proper care in their later years.

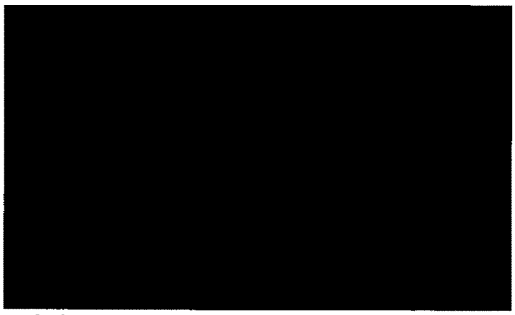
Thank you for your time and attention. I look forward to your response.

Sincerely,

Jasmine E.

Convergence Home Care Services





Dear Senator (Last Name),

I am writing to express my deep concern regarding the recent changes to Medicaid, particularly their impact on our senior citizens. The One Big Beautiful Bill Act has left far too many older adults without the essential care they depend on. As someone who works in home care, I witness firsthand the daily struggles many of our seniors endure. Individuals who were once active, engaged members of our community have now become entirely dependent on limited support from their loved ones.

I would like to share the story of Rolanda, who passed away in June 2025. Rolanda was a warm, fun-loving woman whose life changed dramatically after suffering multiple strokes. These strokes affected her mobility in both her arms and legs, as well as her cognitive functioning, leaving her unable to understand or keep up with the Medicaid changes affecting her care. Despite her challenges, she tried to remain positive, but the system failed her when she needed it most.

Her home care services were removed just two months before her passing as a result of the One Big Beautiful Bill Act. During those final months, she was left alone, depressed, and unable to care for herself. She often expressed frustration and exhaustion from constantly fighting for the care she deserved. She was not married, had no children, and her family lived out of state, leaving her without the support she desperately needed.

Rolanda's experience is not an isolated one. It represents the fear and reality faced by many vulnerable seniors across our state.

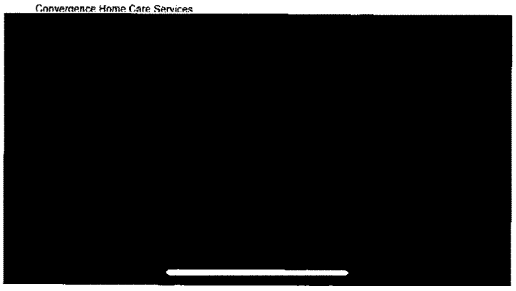
I respectfully urge you to reconsider the impact these policy changes have on individuals who cannot advocate for themselves—those who have contributed to their communities and deserve dignity, safety, and compassion in return. They should not be left without the care they need to live with quality and peace.

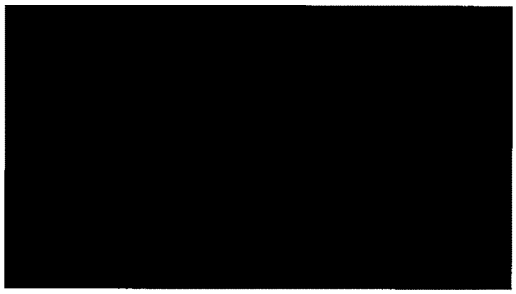
Thank you for your time and attention. I look forward to your response.

Sincerely,

Jasmine E.

Convergence Home Care Services





Dear Senator,

I'm writing this letter to share an account of personal progress, the importance of mental health, substance abuse, and compassion. Home care services play a vital role in supporting the elderly by companionship, routine, and personalized attention, helping with daily tasks and offering consistent emotional support.

In the middle of this year, I started working with a client who's been diagnosed with schizophrenia; he was in an extremely difficult place. He was struggling with alcohol use, significant stress, distrust of others, and episodes of psychosis that included hallucinations. Daily life had become overwhelming and unpredictable; moving forward for him was uncertain, and he wasn't sure what to do or who to go to, being that he was in his 70s with little to no family at all.

With consistent support and the availability of appropriate care, this client has made remarkable progress. Through patience, guidance, and willingness to seek help, he gradually moved from crisis toward stability. The hallucinations that once disrupted their sense of safety have subsided. The stress that dominated his thoughts has eased. Step by step, he regained clarity, trust, and confidence.

Today, he is more relaxed, engaged in our conversations, and hopeful for the future. His progress is a testament not only to their own determination but also to the crucial role that mental-health and recovery services play in helping people reclaim their lives.

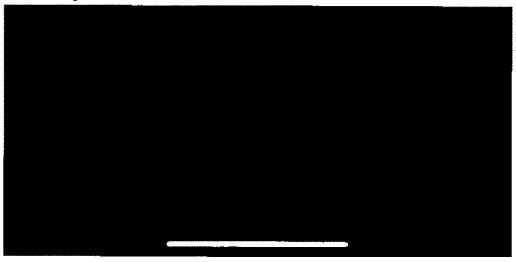
I share this with you because stories like this one are why continued support for mental-health programs, addiction treatment, and community-based recovery services is so essential. When these resources are available, life can change sometimes dramatically and always meaningfully.

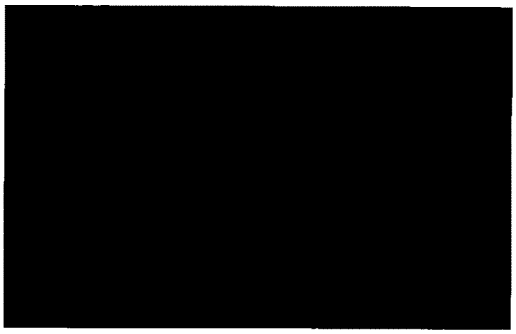
Thank you for your attention to issues that affect the well-being of individuals and families across our state. Your leadership has the power to ensure that more people receive the help they need during their most vulnerable moments.

Sincerely,

Audrey Davidson

Convergence Home Care Services





Dear Senator,

I am writing to highlight the essential role that home care services have played in supporting a client who has faced significant challenges, including multiple surgeries, financial hardship, and being on the edge of homelessness. Despite these obstacles, home care has provided stability, guidance, assistance in finding housing, and day-to-day support needed for the client to regain confidence and manage their recovery safely at home.

Through personalized care, emotional support, and help with daily activities, the client has been able to focus on healing rather than the overwhelming stress of their circumstances. Home care has not only improved their physical recovery but has also strengthened their mental and emotional well-being, empowering them to make progress toward independence and stability in everyday life.

I hope this sheds light on how important home care services are. Thank you for taking the time to read my letter.

Sincerely,

Audrey Davidson

Convergence Home Care Services





Dear Senator,

I am writing to you to express my strong support for increased attention and funding for home care services for the elderly. As life continues, the need for accessible, reliable, and compassionate home-based care is more important than ever. These services are not simply an optional support system; they are essential to the safety, dignity, and overall well-being of millions of seniors across our state and country.

Home care allows elderly individuals to remain in the comfort of their homes, surrounded by a familiar environment and close to loved ones. This stability is not only emotionally meaningful, but it has been shown to reduce hospitalizations, prevent accidents, and improve long-term health outcomes. For many seniors, home care is the difference between living independently and being forced into institutional care they may not want, cannot afford, or medically do not require.

Expanding and strengthening home care programs would not only improve the quality of life for the elderly but also ease the burden on families who frequently act as unpaid caregivers. Many family members struggle to balance work, caregiving responsibilities, and their own well-being.

I urge you to support legislation that increases funding for home- and community-based services, improves wages and training for home care workers, and ensures that elderly residents, regardless of income, can access the care they need to live with dignity. Thank you for your time.

Sincerely,

Audrey Davison

Convergence Home Care Services

December 3, 2025

The Honorable Rick Scott
Chairman
Senate Special Committee on Aging
Washington, DC 20515

The Honorable Kirsten Gillibrand
Ranking Member
Senate Special Committee on Aging
Washington, DC 20515

Subject: Statement for the Record: Aging in Place: The Impact of Community During the Holidays

Submitted Electronically via: Hans_hansen@aging.senate.gov

Dear Chairman Scott and Ranking Member Gillibrand,

LeadingAge is pleased to offer the following statement for the record on the December 3, *Aging in Place: The Impact of Community During the Holidays*.

LeadingAge represents more than 5,400 nonprofit aging services providers and other mission-driven organizations that touch millions of lives every day. Alongside our members and 36 partners in 41 states, we use applied research, advocacy, education, and community-building to make America a better place to grow old. Our membership encompasses the continuum of services for people as they age, including those with disabilities. We bring together the most inventive minds in the field to lead and innovate solutions that support older adults wherever they call home.

In 2026, the oldest baby boomers will turn 80. The older population in 2030 is projected to be more than twice as large as in 2000, growing from 35 million to 73 million and representing 21% of the U.S. population.[i] Complicating the increasing numbers of older people are economic declines in the over-65 group. Many older adults face financial hardship while our social safety net is not keeping up and, in many ways, is being cut back.

Fundamentally, 2025 brought huge changes to the Medicaid program, which is the backbone of our nation's long-term care system and the only payer that funds older adults to remain in their communities with long-term services and supports. In 2022, Medicaid financed over $415 billion dollars of LTSS services, most of which went to home- and community-based services (HCBS). This is 61% of total U.S. LTSS spending. Medicaid is the primary payer for over 60% of nursing home stays. It is estimated that the changes from H.R. 1 will cut over $900 billion over the next 10 years from the Medicaid program (14% of the program's overall budget). The amount of these cuts will vary by state with a potential range of spending cuts from 4% to 20%. These fundamental shifts in Medicaid funding will impact the ability of older adults to remain in their communities. We urge the Committee to advance proposals that ensure the services and supports necessary for aging in community are available to people by investing in housing, services, local neighborhoods, and communities themselves.

Medicare does not cover ongoing LTSS needs. Medicaid finances some LTSS for people who have very limited incomes and assets, and for those whose health and LTSS expenditures drive them into poverty. Individuals at the top of the income spectrum may be able to self-finance care. Others have few options to meet their LTSS needs.

We urge the Committee to support proposals that explore multiple financing mechanisms – both expanding Medicare to cover long-term care services and providing options outside of the Medicare program. For example, there is bipartisan support to invest in options that support family caregivers and The Well-Being Insurance for Seniors to be at Home (WISH) Act was reintroduced in the House this year with bipartisan support. Meanwhile, states are discussing LTSS financing proposals of their own.

While most people prefer to remain in place, at least until they need extensive supports, few reform proposals to date have considered that many people with low incomes have no real options to receive extensive services in any place other than a nursing home. Those that do are threatened by the forthcoming cuts to Medicaid and face a severe shortage of affordable housing in which to receive those services.

To receive home- and community-based services, individuals must have a home. Any viable system to ensure aging in community is possible must include resources to expand the supply of affordable housing for older adults with low incomes. Today's affordable housing programs are so small that they only meet about 30% of the need. Proposals must also ensure that people that do have housing can receive services that help them remain in the community, that help older adults navigate to different care settings and services as their needs change.

In this statement, we highlight the importance of affordable housing and community-based services that often receive less attention in conversations about aging in place as well as home-based care.

The Importance of Stable, Affordable Housing for Older Adults

Older adult homelessness is the fastest-growing type of homelessness in America, and as a country, we need housing solutions that support older adults as they age in community. In addition, stable, accessible housing is a foundational determinant of health for older adults and a prerequisite for the effective delivery of community-based services. Federal housing programs such as the Department of Housing and Urban Development (HUD) Section 202 Supportive Housing for the Elderly, Housing Choice Vouchers, and project-based rental assistance play an essential role in ensuring that low-income older adults can remain safely housed as their functional needs change. Without affordable housing that can accommodate changes in functional needs, many older adults face premature and avoidable transitions to higher-cost settings or experience health and safety risks that exacerbate chronic conditions. Housing stability also enables the efficient delivery of community-based supports, including home-delivered meals, personal care, and access to adult day services and PACE programs.

Strengthening and expanding federal housing subsidies and supporting service coordination within federally assisted housing can help address the homelessness crisis and significantly enhance older adults' ability to age in community while reducing system-wide costs.

We urge the Committee to support investment and expansion of proven affordable housing supply solutions coupled with services and scalability to promote housing stability and aging in community. To ensure ongoing access to community-based services, expanding access to affordable housing access and maintaining our current affordable housing supply are paramount.

Adult Day Services
Adult day programs provide structured supervision, social engagement, cognitive stimulation, and health monitoring throughout the day. They also offer affordable, high-impact support for family caregivers by providing respite, regular schedules, and peace of mind that loved ones are safe and engaged. Attendance at adult day programs allows family caregivers to maintain employment and the household, while providing much needed social and cognitive stimulation to attendees.

Adult day services have been shown to reduce social isolation, support functional maintenance, and help prevent avoidable emergency department visits and hospitalizations. These supports delay the need for more intensive care and services and provide community and purpose for attendees. High quality providers tailor activities, community service, and purpose for attendees through person-centered care planning. Our members report that on average 80-90% of their attendees are experiencing moderate dementia. Staff are trained to provide compassionate and dutiful care to participants with various stages of dementia. Training focuses on communication and de-escalation of behaviors if participants become agitated. During the holidays, when caregivers may be pulled in multiple directions, adult day services can be a critical stabilizing force for both older adults and their families.

Payment rates for adult day services varies significantly by payer and is typically offered by state Medicaid programs under optional waivers as well as by Veteran's Affairs and Older Americans Act (OAA) programs and private pay. States set their program rates for Medicaid, while other payers like OAA or private pay rates are negotiated via contracts. Medicare does not cover adult day services except as an option for respite care in Guiding an Improved Dementia Experience (GUIDE) model being tested by the Center for Medicare and Medicaid Innovation (CMMI) and a limited number of Medicare Advantage plans offer adult day as a supplemental benefit. Many providers cobble together funding from philanthropic organizations or counties to support their missions and provide a community service to locals in need. Adult day centers often struggle to remain viable and to gain recognition for their contribution to keeping older adults in community and any proposal to promote aging in community should include adult day as a part of the solution.

Program of All-Inclusive Care for the Elderly (PACE)
PACE is a comprehensive, interdisciplinary model of care that integrates medical services, LTSS, transportation, rehabilitative therapies, and social supports. It is designed for individuals residing in the community that also meet a clinical threshold for program eligibility. PACE organizations coordinate services through interdisciplinary care teams and day centers that provide stability to participants and staff visibility of participants to monitor health, well-being, and unmet needs. The model blends clinical care, personal support, and social engagement within one care plan illustrates the value of holistic community-based approaches.

Because of the PACE program's role as the care coordinator, provider, and payer, data on participant wellbeing and interventions is integrated which allows for truly individualized care planning and interventions. PACE services are funded as a blend of Medicare and Medicaid payment, where long-term care interventions typically funded by Medicaid offset acute care costs that would be incurred by Medicare. The financial incentives for PACE programs to provide wrap around services to keep participants safe demonstrate how fully integrated programs can be built to promote participant wellness and satisfaction.

There are many barriers that limit PACE growth and access to communities across the country – Congressional action to alleviate these barriers would help to expand this popular, community-based program. For example, PACE programs are limited to enrollment of new participants on the first day of each

month, though individuals' needs don't adhere to calendars. Therefore, when new participants are finally enrolled, many times the delay in accessing services results in expensive early months, as PACE providers stabilize neglected chronic conditions. Additionally, PACE programs are limited in the numbers of applications for expansion that a program can have pending with the Centers for Medicare and Medicaid Services – so those programs that are successful at the model are limited in their ability to expand. As programs consider ways to serve populations in rural areas, they are burdened by physical plant requirements such as available bathrooms or square footage transportation, network requirements to include providers that do not exist in these areas and who do not align with participant needs, and others. The comprehensive and integrated nature of PACE programs would benefits scores of rural and frontier areas, though those populations will continue to miss the opportunity if Congress and CMS do not consider new ways to provide flexibility for PACE programs.

Transportation Challenges for Older Adults

Reliable transportation is a critical component of aging in the community, particularly for older adults who no longer drive and those living with cognitive impairments such as dementia. When transportation is unavailable or inconsistent, older adults face heightened risks of social isolation, food insecurity, missed medical appointments, and avoidable emergency care. Challenges are especially acute in rural areas, where long distances, limited public transit options, and workforce shortages constrain access to essential services. While many communities draw on a patchwork of supports including volunteer driver programs, paratransit, PACE transportation, faith-based networks, and Area Agency on Aging services, these resources are often insufficient to meet growing demand. Current healthcare payer arrangements, including Medicare's focus on medically-necessary and episodic services, rarely cover transportation for social needs or ongoing long-term supports. Medicaid scheduling and reimbursement for transportation remains spotty and unreliable. As a result, older adults frequently experience gaps that undermine continuity of care and contribute to preventable health decline.

Many of our mission-driven members have invested extensive time, energy, and capital in vehicles to transport adult day, PACE, and affordable housing participants to medical appointments and other services vital for their health and community engagement. Funding to acquire vehicles and associated liability insurance burden providers with significant costs. Grants from government sources and donations from local philanthropy are the most common sources of funding for modified vehicles appropriate for our community-based services provider members serving older adults using assistive mobility devices and wheel chairs. Congress should expand funding and incentives to invest in a stronger transportation infrastructure across payers and jurisdictions to ensure older adults can fully participate in community life and access the care and support they need.

Home Based Care

While LeadingAge is pleased to underscore the value of community-based care, care in the home is a critical component of aging in community. Personal care services such as assistance with bathing and dressing are not covered by the Medicare program – and, as detailed above, a funding mechanism whether through Medicare or through a new financing mechanism is essential to support widespread aging in community. Skilled home health under the Medicare program has sustained years of decreased reimbursement making it more challenging for patients to access this critical service as providers have had to cut back on service, close, or delay admissions. We support reforms to create a more sustainable home health benefit that should consider how to better fund the availability of aide services. Aide services are covered in Medicare home health, but the current payment system does not allow providers to offer the services sustainably. The Medicare hospice benefit is also an important service that allows dignified and supported end of life care when done right. LeadingAge supports changes to the hospice benefit that would expand access through

payment for home respite in hospice, expanded inpatient hospice options, and payment for therapies like palliative radiation, dialysis, blood transfusions, and others that would make it easier for people to elect hospice timely.

Improve Information Sharing Across Payers

Community-based interventions like home care, adult day, and home maker services keep people stable and healthy in their communities. Accessible and usable communication across provider types from primary care, hospital, community-based provider, and caregiver do not exist. Multiple platforms and software solutions try to bridge the chasm, but communication and information analysis takes time. Taking a holistic approach to person-centered care would bring privacy-protected information sharing across provider types allowing family caregivers to schedule care and services, in the same location physicians can review upcoming appointments and prescriptions for interactions.

Federal support for health information exchanges and commitments to funding for small and community-based organizations is key to assuring the entire healthcare ecosystem is connected and informed. Understanding key interactions and interventions will allow better informed policy decisions and predictive analysis of interventions that prevent acute episodes. Aging services providers never received any meaningful use dollars and need financial support to ensure that they are able to offer technology-enabled care that will support aging in community in the future.

Policy Considerations to Strengthen Community-Based Aging Supports

As an organization that represents stakeholders across the payer and services continuum, we recognize that no single payer or care model can meet all aging-related needs. Instead, progress will require cross-payer alignment, multi-sector collaboration, and flexible approaches that allow communities to build the infrastructure older adults require.

We respectfully offer the following considerations:

1. **Strengthen the home- and community-based services (HCBS) foundation across states and payers.** Increased federal–state collaboration, stable funding streams, and streamlined access pathways are essential to ensuring older adults can receive the right supports at the right time. Stabilization of these partnerships is more important now than ever, with enactment of H.R.1 reducing Medicaid program capacity in nearly all states.
2. **Expand access to quality community programs such as adult day services and PACE.** Policymakers should consider opportunities to reduce barriers to these programs and ensure sustainable, adequate reimbursement that allows providers to meet rising demand. Elimination of burdensome PACE regulations at the federal level along with congressional support for regulatory flexibility in the service of rural areas would improve access to many new rural populations across the country. Additional federal oversight from Veterans Affairs of the community care program to ensure that Optum and Tri-West understand adult day services and are accurately assessing network adequacy and veterans' abilities to access adult day programs.
3. **Address Affordable Housing Supply Needs.** Expand the supply of affordable and accessible senior housing while preserving and positioning the existing U.S. affordable senior housing portfolio for long-term affordability and resilience.
4. **Promote integration of health and social supports across all payers.** Integrated and coordinated approaches—whether through PACE, managed care, value-based models, or community-led networks—are critical to addressing whole-person needs without prescribing a single pathway. Integration requires commitments of time, energy and financial investment to coordinate information sharing and promote integration among disparate

organizations governed by distinct regulatory frameworks- particularly relating to data and information sharing and privacy.

5. **Support the aging services workforce.**
   Workforce shortages across all settings remain a primary barrier to access. Federal action to strengthen recruitment, training, and retention for direct care workers and community-based staff from both domestic and foreign-born pipelines is essential. Community-based programs like adult day and PACE help relieve stress on local healthcare workforces. When attendees at day programs receive services in group settings, staff are able to efficiently provide care and services to multiple individuals without workforce travel time. These settings create economies of scale, where instead of 1:1 care in the home, one staffer can support six or eight participants over the course of a day. We need more staff across our continuum of services and the resources necessary to ensure jobs in aging services are well-compensated, offer career ladders and lattices, and are well respected.
6. **Address social isolation and caregiver strain as core health issues.**
   Evidence-based interventions such respite services, transportation, social engagement programs, and caregiver supports should be elevated as foundational policy elements of healthy aging. Transportation is a tremendous barrier for older adults and is not covered by traditional health insurance or Medicare. Solutions that provide scheduled transportation to doctor appointments and social programs, particularly in rural areas where ride shares and other public transportation is not an option, will bolster older adult health. Systems reforms that recognize older adults' needs as societal needs will reduce costs and increase availability, improving the healthcare delivery system, long-term services and supports, and accessible infrastructure for all people.

Conclusion

We appreciate the attention of the Chair, Ranking Member, and members of the Committee to older adults' use of the full continuum of services as they age. The need for stable housing and supportive services keeps people in their communities and ensures they can thrive, live, or experience their final wishes in their homes or communities. LeadingAge supports the work of the Committee and is a trusted resource as members have questions about aging services. Questions can be directed to Mollie Gurian at mgurian@leadingage.org.

Thank you.

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[i] Older Americans 2020: Key Indicators of Well-Being (agingstats.gov)

December 4, 2025

To the Members of the Senate Special Committee on Aging and on Disability,

I am writing as a parent of a 26-year-old daughter with Down syndrome to express my deep appreciation for your work and to emphasize the critical importance of supporting community living for older adults and people with disabilities.

Community living allows people like my daughter to lead full, meaningful, and self-directed lives—lives in which they can build relationships, contribute to their neighborhoods, and experience the dignity of choice. For older adults and individuals with disabilities, access to inclusive housing, supportive services, and safe, well-resourced communities is not just beneficial—it is essential for health, independence, and overall quality of life.

Federal leadership and investment in home- and community-based services, accessible transportation, and inclusive housing help ensure that people are not forced into institutional settings simply because community supports are unavailable or underfunded. Strengthening these supports honors the values of autonomy, inclusion, and equal opportunity.

Thank you for your ongoing commitment to policies that allow all people, including my daughter and so many others, to thrive in the communities they call home.

Respectfully,
Debbie Ross

December 2, 2025

Chairman Rick Scott
Senate Special Committee on Aging
628 Hart Senate Office Building
Washington, DC 20515

Ranking Member Kristen Gillibrand
Senate Special Committee on Aging
628 Hart Senate Office Building
Washington, DC 20515

Dear Chairman Scott & Ranking Member Gillibrand,

On behalf of the Muscular Dystrophy Association (MDA) and in service to the neuromuscular disease community, thank you for the opportunity to submit an organizational statement on the importance of programs which support community living for people with disabilities in response to the full committee hearing titled: "Aging in Place: The Impact of Community during the Holidays".

For 75 years, MDA has led the way in accelerating research, advancing care, and advocating for families in the neuromuscular community. Our mission is to empower people affected by muscular dystrophy, ALS, and hundreds of other neuromuscular conditions to live longer, more independent lives, and the programs described in this statement – notably, home and community-based services (HCBS) and Centers for Independent Living (CILs) – are key to achieving that mission.

HCBS & the Neuromuscular Community

Neuromuscular diseases are complex, rare, genetic diseases defined by muscle weakening and often leading to some level of disability. While each disease varies in its progression, affected muscles, and symptoms, and each individual's journey with neuromuscular disease is unique, many rely on HCBS funded by Medicaid in order to live independently and thrive in their communities. These services support people with disabilities in daily tasks including bathing, getting dressed, taking medications, preparing meals, shopping for groceries, and more. As Bryce in Ohio shared with the Dayton Daily News[1] this year:

"Living with spinal muscular atrophy (SMA) presents unique challenges, but my day starts the same as everyone else's. I wake up, read some news and begin my morning routine that

[1] https://www.daytondailynews.com/local/voices-congress-cuts-medicaid-but-the-fight-isnt-over/XKS2QI4YQZG2HBVLCOYOHMCXQE/

Don, my caregiver, helps me to do. Medicaid has enabled me to keep Don employed, and he has given more than a helping hand and increased mobility. He gives me independence and hope.

Before I had a caregiver, most of my summers were spent taking my wheelchair around the same neighborhood path, and that was my only outing for the day. With Don, I go grocery shopping, find fulfillment in work, spend more time with friends, and truly experience what life has to offer – in large part, thanks to Medicaid. Medicaid gives me the freedom to live my life. It's far more than insurance. It gives me the ability to interact with the world around me, to find purpose in work, and to thrive in my community."

Despite the important role of HCBS in enabling independent living, these services can be extraordinarily difficult to access due to decades of underinvestment. HCBS is not a mandatory benefit under Medicaid, despite being the primary payer for 60% of home and community-based services. This can lead to lack of adequate funding that in turn leads to long waiting lists for services, and ultimately, unnecessary institutionalization, an affront to the promise of *Olmstead*, which held that segregation of people with disabilities is discrimination, in violation of Title II of the Americans with Disabilities Act.

It is important to uplift the key role of Medicaid in enabling community living for the neuromuscular disease community, especially given the devastating cuts the program saw this summer. As MDA repeatedly warned during the budget reconciliation process, the cuts to Medicaid in the One Big Beautiful Bill Act are likely to lead to further reductions in HCBS and longer waiting periods for life-enabling services. These cuts, and in particular, the restrictions on provider taxes, will have dire implications on access by altering Medicaid financing in a manner that places serious pressure on states, which will be forced to reduce coverage or cut payment rates to home care workers and direct support professionals. This will negatively impact the neuromuscular community's ability to receive the care they need to thrive. As Bryce continued, without Medicaid-funded HCBS, his independence is uncertain:

"I may not be able to get to appointments, get out of bed, or put a shirt on in the morning. I already budget meticulously because I can only physically work so many hours, and I can't afford to work any fewer hours. I need my job to pay for my housing, groceries, and bills. It's because I have a caregiver funded through Medicaid that I can work at a job I love. I can spend time with loved ones and fully embrace each day because he can transport me where I need to go. Without Don, I would be trapped inside an apartment I can no longer afford."

Bryce is not the only member of the neuromuscular community to uplift the importance of HCBS in light of Medicaid cuts, now realized. Shelley, another Ohioan, shared in the Ohio Capital Journal[2] this year:

"Many think Medicaid is simply government-subsidized health insurance, but for me, and millions of others like me, it is so much more. It allows me to live independently in a home that I own. It pays for modifications like a ramp and roll-in shower that makes life's routines easier. Most importantly, Medicaid pays the wages of my caregivers who support my personal care needs and household tasks. As a 59-year-old, it enables me to stay employed, leave the house, and live a fulfilling life. Without it, these things would be impossible because I would be stuck in bed with no one to care for me.

Any cuts or barriers to enrollment will have cascading impacts across the United States, putting the health and independence of Medicaid beneficiaries at risk. For those of us living with neuromuscular diseases, Medicaid allows us to pay for long-term care. If Medicaid suffers funding cuts, the consequences will be significant – we will likely face delayed treatments, be unable to afford life-saving medications, and have increased difficulty affording the homecare assistance we need to be healthy and fulfilled."

Eric, an attorney in West Virginia living with SMA type 2, wrote in the Charleston Gazette-Mail[3]:

"Medicaid's HCBS waiver programs are what make independent living possible for people like me. These programs, like West Virginia's Aged and Disabled Waiver (ADW), allow individuals to remain in their homes with attendant care, rather than being institutionalized. I've used these services not to survive but to contribute. To work. To live.

I was fortunate to have parents who could care for me until I went to college. I developed a plan, depending on my health, to find a job that I could physically do to increase my independence (although some might argue that being an attorney is my biggest disability). State waiver programs gave me a shot, one that lets people like me potentially contribute as part of the taxpaying workforce.

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[2] Medicaid enables fulfilling livelihoods in Ohio and across America • Ohio Capital Journal
[3] https://www.wvgazettemail.com/opinion/op_ed_commentaries/eric-arnold-look-both-ways-before-crossing-out-medicaid-opinion/article_2f42dfc4-fa2a-4503-b62b-f77762cd79e6.html

When waiver programs get slashed, families will be forced to adjust their jobs – or leave them entirely – to provide the care no longer funded. The cost of private, in-home attendant care is staggering, especially for a workforce already gutted by the economy and the opioid crisis. Or they'll be left with no choice but to place their loved one in a care facility. Those will quickly become oversaturated, driving demand for help in jobs like certified nurse aides, orderlies, and home health techs – roles that already struggle to recruit without substantial pay increases. And those increases? They'll either cut into a family's budget, or the state's. And here's what every West Virginian already knows: when faced with that choice, most families will walk away from taxable work to become unpaid caregivers."

MDA supports policies that strengthen access to HCBS and eliminate waitlists through increased Medicaid and grant funding, as well as increase the availability and quality of the direct care provider workforce. At a minimum, MDA urges members of the Senate Special Committee on Aging to support the HCBS Relief Act (S. 2076/H.R. 2049), which would increase the federal Medical Assistance Percentage (FMAP) by 10 points for HCBS provided in FY26 and FY27 for the purposes of enhancing, expanding, or strengthening HCBS. Examples of permitted activities include increasing reimbursement rates for home health aides; providing paid sick days and medical leave; providing HCBS to those on waiting lists; and to recruit new home health workers.

Centers for Independent Living (CILs) & the Neuromuscular Community

In addition to HCBS, Centers for Independent Living, or CILs, are essential to achieving MDA's mission of empowering the neuromuscular community to live longer, more independent lives. These centers, a product of the disability rights movement, uniquely center the agency of people with disabilities by being operated and staffed by people with disabilities themselves, focused on community integration, advocacy, and peer support. Importantly, CILs are centered in the community, and help individuals live independently within their own homes (as opposed to providing residential or institutional care) by connecting the community with skills, transition services, advocacy, and peer support.

MDA thanks the Committee for convening this hearing and uplifting the important role of HCBS and CILs in enabling community living for people with disabilities. We urge the Committee to continue to shine a light on how we make these services more comprehensive and accessible for all. In addition, we urge the Committee to study and strengthen the many other programs that enable individuals affected by neuromuscular conditions to fully participate in the community, including: educational supports provided through the IDEA; housing programs that serve people with disabilities; legal assistance

through state protection and advocacy systems; vocational rehabilitation services that open doors to employment; and other programs powering independence for individuals with disabilities.

If you have questions regarding MDA's comments, please contact Shannon Wood, Director of Disability Policy at swood@mdausa.org.

Sincerely,

Shannon Wood
Director of Disability Policy
Muscular Dystrophy Association



Outside Witness Testimony of
Meals on Wheels America

Submitted to the U.S. Senate Special Committee on Aging
Hearing: ***Aging in Place: The Impact of Community during the Holidays***

December 4, 2025

On behalf of Meals on Wheels America, we are writing to provide this outside witness testimony for the hearing, "Aging in Place: The Impact of Community during the Holidays," held on December 3, 2025. Meals on Wheels America is the national leadership organization representing more than 3,000 community-based senior nutrition programs operating in virtually every county across the country.[1] Our members deliver **251 million meals to more than 2 million seniors annually** and provide critical social connection and daily safety checks to older adults who are often living alone, homebound, or coping with mobility limitations and chronic health conditions. Together, we work toward a vision in which every older adult can age with nourishment, independence, and dignity.

End the Wait

We are amid an affordability crisis for low-income older Americans, which is hitting right at the holiday season, when struggles with loneliness and hunger are felt even more acutely. For millions of seniors, the holidays are the loneliest time of the year, as they face silent nights, silent weeks, silent months – even silent years – hoping someone will care. No senior should have to wait in isolation, struggling behind closed doors hoping for basic care like nutritious meals and moments of connection. That's why Meals on Wheels America launched the Silent Night campaign[2] to call attention to the widespread unmet need and build support to **End the Wait** for seniors who need Meals on Wheels.

Unfortunately, chronic federal funding shortfalls, a growing need for services for America's rapidly aging population, and increasingly high costs for food, fuel, and program operations limit the ability of local Meals on Wheels programs to reach the vulnerable older adults in need across the country. The challenges of senior hunger and isolation are being exacerbated now by delays for reimbursements to local Meals on Wheels providers due to the government shutdown[3], cuts to SNAP[4] and Medicaid[5] that will lead to benefit losses for many low-income older adults and high costs for food and essentials, making it all the more difficult for many to meet their basic needs.

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[1] Meals on Wheels America. "About." *Meals on Wheels America.* https://www.mealsonwheelsamerica.org/about/

[2] Ending Senior Loneliness and Hunger | Help End Silent Nights

[3] Government Shutdown: The Impact on Meals on Wheels

[4] SNAP Work Rules Strain Older Adults, States

[5] What's in the Budget Reconciliation Act of 2025 and What Does it Mean for Low-Income Older Adults' Access to Health and Long-Term Care? - Justice in Aging

According to the most recent Meals on Wheels America data, nearly one in three local providers have waitlists, and nearly 46,000 seniors are waiting nationally for services.[6] The typical wait is four months, and in some areas older adults have waited more than two years for the nutritious meals and moments of connection and care they need and deserve.[7] As one program leader poignantly expressed: "It's the worst feeling to have to tell someone, 'We have a waitlist.' You can't speak those words without feeling emotion because you're telling someone who's starting." Without additional federal investment and support, more providers will be unable to meet growing requests for help and will be forced to have such heartbreaking conversations with seniors in need they are not able to serve.

With increased funding and strong congressional backing for the OAA Nutrition Program, our nation can ensure that more of our vulnerable seniors receive the meals and social connection they need to remain healthy and independent at home. Ending the wait for services is essential to support aging in place for millions of older Americans who rely on Meals on Wheels. Meals on Wheels America urges Congress to swiftly reauthorize the Older Americans Act by advancing the bipartisan OAA reauthorization bill reintroduced in the Senate and providing emergency supplemental funding for the OAA Nutrition Program for FY26 to help address the widening crises of senior hunger and isolation, following the bipartisan call for a funding boost recently made by Representatives Vern Buchanan (R-FL 16) and Suzanne Bonamici (D-OR 1).[8]

Social Connections for Older Americans

While nutrition is central to our mission, the work of Meals on Wheels programs extends far beyond the delivery of food. Daily interactions with volunteers and program staff, which may be the only person a senior sees that day, provide meaningful and consistent social connection. These touch points reduce loneliness, contribute to improved health outcomes, support emotional well-being, and help identify emerging health or safety concerns before they escalate into emergencies.

Today, millions of seniors experience social isolation, leaving them at risk for a multitude of adverse and costly health issues. Studies show the highest rates of social isolation are found among older adults, putting seniors at risk for high blood pressure, heart disease, obesity, a weakened immune system, anxiety, depression, cognitive decline, Alzheimer's disease, and even

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[6] Meals on Wheels America, *Fact Sheet: The Crisis of Waitlists for Meals on Wheels*, accessed November 30, 2025, https://www.mealsonwheelsamerica.org/research/fact-sheet-the-crisis-of-waitlists-for-meals-on-wheels/

[7] Meals on Wheels America, *2024 Membership Impact Report*, August 2025, https://www.mealsonwheelsamerica.org/wp-content/uploads/2025/08/2024-Membership-Impact-Report_8.4.25.pdf

[8] Ahead of the Thanksgiving Holiday, Buchanan and Bonamici Lead Bipartisan Push to Strengthen Preventive Nutrition Services for Seniors | Press Releases | Congressman Vern Buchanan

death. Research demonstrates that social isolation among older adults leads to an extra $6.7 billion (about $21 per person in the US) in Medicare spending per year in 2012 dollars, associated with the expenditures of having high blood pressure or arthritis.[9]

Some of the most vulnerable seniors that the Older Americans Act serves, those who are frail, homebound, and socially isolated, rely on the home-delivered meal programs. Despite the well-established link between healthy aging and regular socialization, millions of seniors struggle to meet their basic human needs. Local, community-based organizations play a critical role in addressing the social and nutritional needs of our nation's older adults and the impact of these services on seniors' lives is powerful.

During the holiday season, when feelings of isolation often intensify, these interactions become even more significant. Community-based Meals on Wheels providers host holiday gatherings, deliver special meals, and provide thoughtful items such as blankets, winter supplies, pet food, and holiday cards and decorations. These small gestures serve as powerful reminders that older adults are valued and not forgotten during a time that can be especially difficult for those who are alone.

Across the country, Meals on Wheels programs have stories about the creation of deep and lasting connections during the holiday season and beyond.

- One senior in a creative-arts program offered by the CICOA Aging & In-Home Solutions shared: "This was a great time spent with people I now can call friends. I have painted pictures that taught me to step outside my box. Thank you for teaching me how to make something I can be proud to display and techniques I can share with my grandchildren."
- An older adult in a friendly-visit and call program run by KC Kosher Meals on Wheels described: "Before the visits started, I would go days without speaking to anyone. It felt like the world had forgotten me. Now, every week, I look forward to hearing that knock on the door or the phone ringing. It gives me something to smile about and reminds me that I still matter."
- And from MOW Central Indiana, a friendly-visit senior named Hope said it best: "Sometimes, all it takes is one person dropping by to remind you you're not alone."

[9] Lynda Flowers et al., *Social Isolation and Medicare Spending Among Older Adults*, AARP Public Policy Institute & Stanford University, November 27, 2017, https://www.aarp.org/medicare/high-price-of-social-isolation-study-2017/

These personal testimonies illustrate the powerful impact of Meals on Wheels, not just providing nutrition, but restoring dignity, joy, and meaningful human connection during a time when loneliness often intensifies.

The Case for Meals on Wheels and the Older Americans Act: Evidence on Senior Isolation
Our report, The Case for Meals on Wheels: An Evidence-Based Solution to Senior Hunger and Isolation, examined 38 studies conducted from 1996 to 2023 and consistently found that Meals on Wheels reduces loneliness and improves seniors' emotional, physical, and social well-being.[10]

Key findings include:

- **Reduced social isolation and loneliness:** Multiple studies found that home-delivered meals reduce feelings of loneliness, especially among older adults living alone. The simple, consistent human contact provided during meal deliveries, wellness checks, and friendly-visit programs is a critical safeguard against the harms of social disconnection.
- **Improved emotional well-being:** Participants reported feeling more hopeful, connected, and supported when receiving meals. Studies show that these regular social touchpoints directly improve mental health, helping prevent depression and emotional decline.
- **Reduced falls and increased safety at home:** Safety checks performed during meal delivery not only ensure older adults' well-being but also reduce risks associated with being isolated at home. Fewer falls and hazards mean fewer emergencies and greater confidence aging in place.
- **Reduced use of costly health care services:** Studies found that seniors receiving home-delivered meals, including socially oriented programs, experienced fewer emergency [11]room visits, hospitalizations, and readmissions. Preventing crises linked to isolation saves both lives and taxpayer dollars.
- **Increased ability to age in place:** Nearly all (92%) of home-delivered meal recipients report that Meals on Wheels helps them remain independent at home. Because isolation is a major factor pushing seniors prematurely into institutional care, social connection paired with nutrition is essential.[12]

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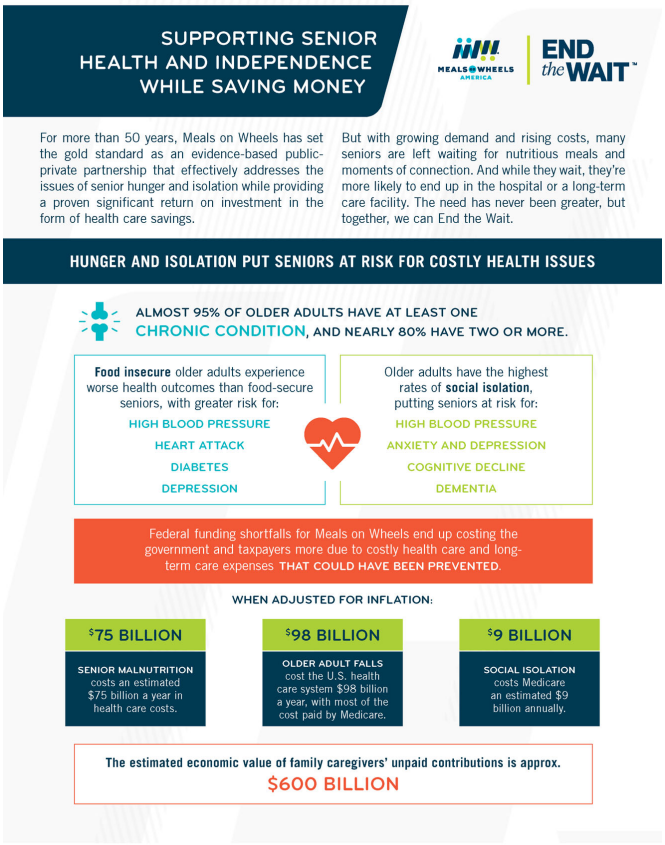
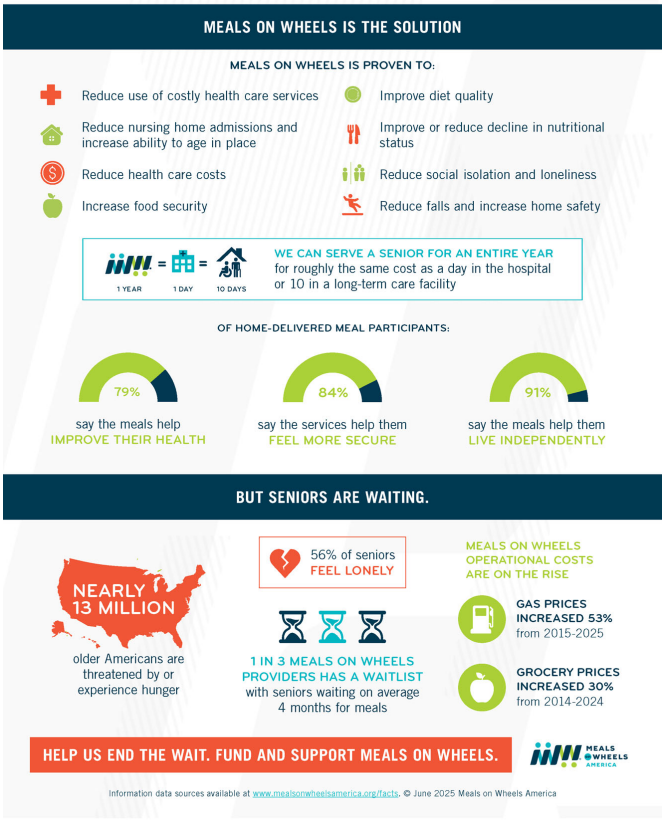
[10] Meals on Wheels America, *The Case for Meals on Wheels: An Evidence-Based Solution to Senior Hunger and Isolation* (Arlington, VA: Meals on Wheels America, 2023), https://www.mealsonwheelsamerica.org/thecase
[11] Meals on Wheels America, *The Case for Meals on Wheels*.
[12] U.S. Administration for Community Living, *2022 National Survey of Older Americans Act Participants*, accessed December 2, 2025, https://acl.gov

These outcomes underscore a simple but urgent truth: the consequences of senior isolation are costly and preventable, and Meals on Wheels delivers one of the most effective national interventions available today.

However, access to the critical lifeline Meals on Wheels services offer depends on congressional support for protecting Older Americans Act programs and ensuring increased federal funding to enable community-based providers to meet the profound social and emotional needs of our rapidly growing senior population.

The holidays spotlight the loneliness, hunger, and hardship too many older adults experience, and these challenges persist long after the decorations come down. This season, Meals on Wheels providers need additional federal support as they are doing everything they can to ensure no senior is left hungry or alone.


SUPPORTING SENIOR HEALTH AND INDEPENDENCE WHILE SAVING MONEY
MEALS ON WHEELS AMERICA
END the WAIT™
For more than 50 years, Meals on Wheels has set the gold standard as an evidence-based public-private partnership that effectively addresses the issues of senior hunger and isolation while providing a proven significant return on investment in the form of health care savings.
But with growing demand and rising costs, many seniors are left waiting for nutritious meals and moments of connection. And while they wait, they're more likely to end up in the hospital or a long-term care facility. The need has never been greater, but together, we can End the Wait.
HUNGER AND ISOLATION PUT SENIORS AT RISK FOR COSTLY HEALTH ISSUES
ALMOST 95% OF OLDER ADULTS HAVE AT LEAST ONE CHRONIC CONDITION, AND NEARLY 80% HAVE TWO OR MORE.
Food insecure older adults experience worse health outcomes than food-secure seniors, with greater risk for:
HIGH BLOOD PRESSURE
HEART ATTACK
DIABETES
DEPRESSION
Older adults have the highest rates of social isolation, putting seniors at risk for:
HIGH BLOOD PRESSURE
ANXIETY AND DEPRESSION
COGNITIVE DECLINE
DEMENTIA
Federal funding shortfalls for Meals on Wheels end up costing the government and taxpayers more due to costly health care and long-term care expenses THAT COULD HAVE BEEN PREVENTED.
WHEN ADJUSTED FOR INFLATION:
$75 BILLION
SENIOR MALNUTRITION costs an estimated $75 billion a year in health care costs.
$98 BILLION
OLDER ADULT FALLS cost the U.S. health care system $98 billion a year, with most of the cost paid by Medicare.
$9 BILLION
SOCIAL ISOLATION costs Medicare an estimated $9 billion annually.
The estimated economic value of family caregivers' unpaid contributions is approx.
$600 BILLION


MEALS ON WHEELS IS THE SOLUTION
MEALS ON WHEELS IS PROVEN TO:
Reduce use of costly health care services
Reduce nursing home admissions and increase ability to age in place
Reduce health care costs
Increase food security
Improve diet quality
Improve or reduce decline in nutritional status
Reduce social isolation and loneliness
Reduce falls and increase home safety
1 YEAR = 1 DAY = 10 DAYS
WE CAN SERVE A SENIOR FOR AN ENTIRE YEAR
for roughly the same cost as a day in the hospital or 10 in a long-term care facility
OF HOME-DELIVERED MEAL PARTICIPANTS:
79%
say the meals help IMPROVE THEIR HEALTH
84%
say the services help them FEEL MORE SECURE
91%
say the meals help them LIVE INDEPENDENTLY
BUT SENIORS ARE WAITING.
NEARLY 13 MILLION
older Americans are threatened by or experience hunger
56% of seniors FEEL LONELY
1 IN 3 MEALS ON WHEELS PROVIDERS HAS A WAITLIST
with seniors waiting on average 4 months for meals
MEALS ON WHEELS OPERATIONAL COSTS ARE ON THE RISE
GAS PRICES INCREASED 53% from 2015-2025
GROCERY PRICES INCREASED 30% from 2014-2024
HELP US END THE WAIT. FUND AND SUPPORT MEALS ON WHEELS.
MEALS ON WHEELS AMERICA
Information data sources available at www.mealsonwheelsamerica.org/facts. © June 2025 Meals on Wheels America

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SOUTH FLORIDA
SunSentinel

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Broward schools' office lease plagued by missteps

By Scott Travis
South Florida Sun Sentinel

The Broward School District made a series of blunders when it entered into a $2.6 million office rental contract, including failing to demonstrate a need for the space, failing to negotiate favorable terms for the lease and selecting a space that was too small to meet the district's needs, public documents reveal.

Superintendent Howard Hepburn sent a three-page after-action review to School Board members on Dec. 31, explaining what prompted the district to rent space from the nonprofit group Handy to house more than 100 facilities employees, as well as lessons learned. The South Florida Sun Sentinel also identified a number of questionable actions during a review of public records, prompting Hepburn to send out an updated review on Nov. 21.

"We continue to acknowledge that there were issues associated with the lease," district spokesman John Sullivan told the Sun Sentinel. "The Superintendent has been closely reviewing all processes involved and initial corrective measures have already been implemented. Staff will continue making improvements to ensure stronger oversight, clearer review processes, and adherence to School Board policy."

The School Board on June 17 approved the lease with Handy, whose full name is Help-

Turn to Contract, Page 8



Former Miami Dolphin John Offerdahl and his wife, Lynn, right, deliver a week's worth of meals to Barbara Mundy, 93, in her Deerfield Beach home on Nov. 20. The delivery is part of Offerdahl's foundation Hands-Off Meals delivery to seniors. CARLINE JEAN/SOUTH FLORIDA SUN SENTINEL

Offerdahl nourishes seniors' bodies and souls

Former Dolphin's Hand-Off Meals program helps more than 450 seniors (and wants your help)



Dave Hyde

John Offerdahl sits on the couch beside 93-year-old Barbara Mundy, who turns to hug him and says, "Aren't you handsome?"

The former Miami Dolphins linebacker laughs. "This is why I like to come see her."

"She's the heart," says Mundy.

For the next half-hour, they talk about things big and small at her Deerfield Beach apartment with Offerdahl's wife, Lynn and their friend and co-worker, Ellen Crane. Only as they're about to leave does the reason for their visit come up.

"Should I put the food in the refrigerator?" Offerdahl asks of the 10, prepackaged meals of fresh food brought from Offerdahl's Off-the-Grill restaurant in Lighthouse Point.

Mundy is one of more than 450 seniors across Broward receiving these weekly meals as part of his restaurant's Hand-Off Meals program, a non-profit

Turn to Hyde, Page 12

2 in Guard shot near White House

500 more ordered to DC; attack called 'targeted'

By Alanna Durkin Richer and Gary Fields
Associated Press

WASHINGTON — Two West Virginia National Guard members who deployed to the nation's capital were shot Wednesday just blocks from the White House in a brazen act of violence that the mayor described as "targeted."

FBI Director Kash Patel and Washington Mayor Muriel Bowser said the Guard members were hospitalized in critical condition.

The shooting unfolded as the presence of troops in the nation's capital and other cities around the country has been a flashpoint issue for months, playing out against the backdrop of public debate about the Trump administration's use of the military to combat what officials cast as an out-of-control crime problem.

Jeffrey Carroll, an executive assistant DC police chief, said investigators had no

Turn to Shooting, Page 2

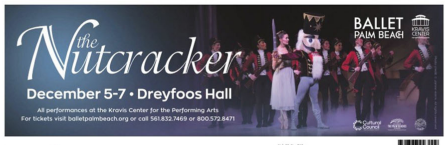
Shutdown effects linger into Thanksgiving

By Adam Geller
Associated Press

She had it figured down to the last dollar. The looming insurance payment, balanced against the hard-earned paycheck. The cost of keeping her children fed, covered mostly with government SNAP assistance. And when Shelby Williams reviewed the family budget for November, she told herself that this month would truly be one for thankfulness.

After living with her parents for more than two years, Williams and her two children were finally moving into an apartment of their own in her hometown of Reeds

Turn to Effects, Page 6



Vol. 65, No. 331
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Hyde

Front Page /

venture to help homebound elderly. The idea is to nourish them with more than just food, too.

Friends. Laughs. A new community. That's the idea here, and something Offerdahl wants to talk to you about, as you'll soon see.

"We can make this such a good program," he says.

It's Thanksgiving, a time to be thankful and admit sometimes you get lucky as a community in ways you don't even grasp at the time. Four decades ago, Offerdahl sat at his home in Sun Prairie, Wis., and took a phone call on NFL draft day from San Francisco 49ers coach Bill Walsh, who said the defensive lineman's team would be moving to the Bay Area.

Offerdahl took the phone off the hook to watch the next draft pick play out. Only San Francisco didn't draft him. It traded the pick. Offerdahl quickly put the phone back on the receiver, and it rang immediately.

"Offerdahl, you're a Miami Dolphin," coach Don Shula said.

Yes, sometimes you get lucky as a community because the Dolphins didn't just get a linebacker who would go through to sit in the Pro Football Hall of Honor today. It got a man who raised a family and carried himself in ways that showed his worldview was more than 100 yards.

As a player, he once drew into a canal and helped rescue a driver who had driven off the road. He once drove to Homestead during Hurricane Andrew and provided some bagels from his former restaurant, Offerdahl's Bagels, which he built to the point of selling it to Einstein's Bagels. Years after he left South Florida, he held the Go Long Gift Off, a community mix of food, football and charity.

So, this Hand-Off Meals program is just the extension of who he's always been, even if he never saw it coming.

"The opportunities kept pulling me back to South Florida," he said.

It started in 2020 when Dolphins owner Steve Ross got the team's alumni restaurateurs — Offerdahl, Kim Bokamper, Bob Brudzinski — to provide meals during the pandemic for the homebound elderly from SunStar Studios. There Offerdahl's team how to package fresh food



Former Miami Dolphin John Offerdahl, delivers a week's worth of meals to Barbara Mundy, 93, in her Deerfield Beach home on Nov. 20. The delivery is part of Offerdahl's foundation Hands-Off Meals delivery to seniors. CARLINE JEAN/SOUTH FLORIDA SUN SENTINEL

in meals.

It expanded the following year when Broward officials faced an emergency of people needing food as the pandemic lengthened. They knew of Offerdahl through relationships in the Gridiron Grill-Off. They used government funds to help the restaurant owner deliver meals around the county.

County officials then encouraged him to apply for a government grant through the Older American Act, which provides funding for meal programs like Meals On Wheels.

"I'd never heard of the Older American Act," Offerdahl said.

His four restaurants across Broward (a fifth is in the Fort Lauderdale airport), became one of three services to supply home-bound seniors in Broward. It was the only one that served the entire state, too. Mundy for one, said how she loves the chef salad with turkey that's delivered.

"Try to give a frozen salad to someone," Offerdahl says. "It doesn't work."

The program was fresh food meant higher costs. Offerdahl got the county's approval to allow his restaurant's venture to become a non-profit organization, so donations could be secured. His previous relationships with the likes of the Jim Moran Foundation and the Community Foundation of Broward literally bore fresh fruit for this new program.

Offerdahl understood the funding and knew how it greased operation, Lynn Offerdahl then provided its heart. She accompanied a volunteer and the volunteer's teenage daughter to visit a homebound woman as part of a "get to know" food delivered of Heart-to-Heart conversation. She was struck by the interaction between them.

"We walked in the door, and they delivered the food, and the (homebound woman) asked the daughter, Hey, Christina, can you make a pot of coffee?' Lynn Offerdahl said. "She went right into the kitchen and the woman says, 'How is your swim meet? I've been praying for you.' And the girl's like, 'Thank you so much.'

"Later, I said, 'John, I wish we could find a way to do the governor's proclamation with the way we've been doing it with volunteers like that, because that's the missing piece.'

"I mean, the food is important. But that relationship with the food is wonderful. These people are starved for human interaction."

This is where you come in. The Offerdahls want to make a sales pitch. They're looking for volunteers to deliver the food. They mostly use paid drivers now — "And they're great," John said.

Volunteer drivers can make the program special, though. Both sides, the driver and homebound recipient, get to see a new face. This helps seniors stay at their homes, so there's a quality-of-life aspect to it. It also keeps down government costs in assisted living.

Their program has 31 volunteer drivers. They include Lynn Offerdahl, who takes an hour every Tuesday morning to deliver food to two people and Crane, who now only delivers food to Mundy in what she calls a "feel-good moment of my week," but has a monthly newsletter for all those getting food to help make it a community.

"Sometimes I think it volunteers is a lot, and sometimes I don't," John said. "We'd love to get up to 150 by the end of the year, even if that's a big number. But don't tell anyone that. You never want your team to know it's not going to get to the Super Bowl."

In creating this program, Offerdahl has become a champion for private and public partnerships in food delivery. He'll talk Dec. 2 in Washington at a Senate hearing on aging about the benefits of home-delivered meals. Maybe he should take Mundy with him. She has plenty to say, like why she loves making new friends.

"Who wouldn't be friends with someone as big and strong as him," she says of Offerdahl. Soon, she says, "I like the shrimp pasta they bring, too."

Yes, sometimes you get lucky as a community. Sometimes, the star linebacker is the star in the locker. Sometimes, decades after football, you realize how much he's a star in the larger community. And you realize just how fortunate we were San Francisco didn't draft him.

For information on how to volunteer, go to handsffmeals.com.

SunSentinel MONEY

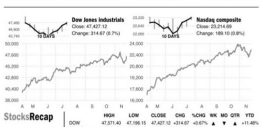
MARKET ROUNDUP

DOW 47,427.12 ▲ 314.67 0.67%

NASDAQ 23,214.69 ▲ 189.10 0.82%

S&P 500 6,812.61 ▲ 46.73 0.69%

GOLD 4,165.20 ▲ 25.20 0.61%





StocksRecap

	NYSE	NASD
Vol. (in mil.)	4100	3773
Prev. Volume	4882	4191
Advanced	1890	2198
Declined	776	1393
New Highs	96	80
New Lows	9	59

	HIGH	LOW	CLOSE	CHG	%CHG	WK	MO	QTR	YTD
DOW	47,571.40	47,196.15	47,427.12	+314.67	+0.67%	▲	▼	▲	+7.48%
DOW Trans.	16,633.89	16,235.07	16,521.32	+129.97	+0.79%	▲	▲	▲	+4.90%
DOW Util.	1,004.83	991.08	1,004.78	+13.70	+1.38%	▲	▲	▲	+14.00%
NYSE Comp.	21,789.51	21,561.73	21,713.13	+161.38	+0.75%	▲	▲	▲	+13.70%
NASDAQ	23,290.56	23,074.38	23,214.69	+189.10	+0.82%	▲	▲	▲	+20.20%
S&P 500	6,851.44	6,783.87	6,812.61	+46.73	+0.69%	▲	▲	▲	+15.83%
S&P 400	3,316.72	3,271.11	3,293.59	+19.98	+0.61%	▲	▲	▲	+5.53%
Wilshire 5000	68,159.61	67,467.44	67,957.75	+460.38	+0.68%	▲	▲	▲	+15.24%
Russell 2000	2,302.96	2,404.90	2,446.12	+20.14	+0.82%	▲	▲	▲	+11.46%

InterestRates

The yield on the 10-year Treasury note fell to 3.994%. Yields affect interest rates on mortgages and other consumer loans.

	PRIME	FED FUNDS
YEST	7.50	3.88
1 MO AGO	7.50	3.88
1 YR AGO	7.50	4.38

TREASURIES	LAST	YVS	CHG	WK	MO	QTR	YRS AGO
3-month T-bill	3.85	3.83	+0.02	▼	▲	▼	4.35
6-month T-bill	3.79	3.77	+0.02	▼	▲	▼	4.31
1-year T-note	3.61	3.60	+0.01	▼	▲	▼	4.11
2-year T-note	3.46	3.46	+0.01	▼	▼	▼	3.91
5-year T-note	3.56	3.55	+0.01	▼	▼	▼	3.96
10-year T-note	3.99	4.00	-0.01	▼	▲	▼	4.41
30-year T-note	4.64	4.66	-0.02	▼	▲	▼	4.55

CONSUMER RATES	NAT'L AVG	WK AGO	MO AGO	YRS AGO
48-month new car loan	5.69 ▼	6.90	7.19	7.02
Money Market Account	0.41 ▼	0.43	0.43	1.47
1-year cd	1.66 ▼	1.92	1.99	3.26
$30K Home equity loan	8.31 ▲	8.14	8.45	8.23
30-year fixed mortgage	6.36 ▲	6.32	6.06	7.12
15-year fixed mortgage	5.51 ▲	5.72	5.72	6.41

ForeignExchange

	CLOSE	CHG	%CHG	MO AGO	YR AGO
British Pound (GBP/USD)	1.3238	-.0100	-.02%	1.3063	1.2265
Canadian Dollar	1.4040	-.0200	-.00%	1.3727	1.4040
Euro (EUR/USD)	1.1550	-.0100	-.00%	1.1385	1.0496
Japanese Yen	156.441	-.0250	-.02%	142.79	153.06
Mexican Peso	18.3361	+.0087	+.05%	19.230	20.838
Israeli Shekel	3.0906	+.0000	+.00%	3.0389	3.9429

LOCAL STOCKS

NAME	TICKER	LAST	CHG	%CHG
3M	MMM	151.47	+0.64	+0.42%
AT&T	T	23.62	-0.04	+0.17%
Abbott Laboratories	ABT	126.34	+1.49	+1.19%
Adobe	ADBE	377.62	-2.23	-0.59%
Allegion PLC	ALLE	166.67	-0.42	-0.25%
Alphabet Cl.	GOOG	320.39	-0.08	-0.02%
Alphabet C	GOOGL	321.17	-0.08	-0.02%
American Airlines	AAL	12.66	+.07	+0.56%
American Express Co.	AXP	363.97	+1.33	+0.37%
Anheuser-Busch	BUD	61.66	-0.79	+0.51%
Apple	AAPL	277.55	+.69	+0.25%
Astronova	ALTR	10.33	+.08	+0.78%
Autonation Inc.	AN	219.59	-6.79	-2.99%
Avangrid	AGR	37.68	+.19	+0.51%
BHP Group Ltd.	BHP	53.68	+1.01	+1.92%
BP PLC	BP	35.59	+.34	+0.97%
Bank of America	BAC	50.98	+.07	+0.14%
Bank of Nova Scotia	BNS	58.97	+1.10	+1.90%
Barclays PLC	BCS	33.38	+.09	+0.27%
Berkshire Hath A	BRK.A	787400.00	+600.00	+0.13%
Berkshire Hath B	BRK.B	511.22	+1.04	+0.20%
Best Buy	BBY	69.66	+.08	+0.11%
Boeing	BA	211.48	+.68	+0.32%
British American Tobacco PLC	BTI	57.87	+.19	+0.33%
Brown & Brown Inc.	BRO	80.45	-0.66	-0.73%
Capital One Financial Corp.	COF	217.47	+3.63	+1.70%
Capri Holdings Ltd.	CPRI	25.63	+.73	+2.93%
Carnival Corp.	CCL	25.41	-0.09	-0.35%
Caterpillar Inc.	CAT	615.00	+2.00	+0.33%
Chesapeake Utilities Corp.	CPK	118.36	+1.16	+0.97%
Chevron Corp.	CVX	149.01	+.56	+0.37%
Cisco Systems Inc.	CSCO	76.67	-0.20	+0.26%
Citigroup	C	102.39	+1.30	+0.25%
Clorox	CLX	107.76	+.66	-0.71%
Coca-Cola	KO	71.99	+.47	+0.71%
Colgate-Palmolive Co.	CL	87.38	+.49	+0.56%
ConocoPhillips	COP	97.09	+.47	+0.37%
Costco Wholesale Corp.	COST	895.30	+13.92	-0.91%
Crocs Inc.	CROX	85.46	-0.28	-0.31%
Cross Country Health	CCRN	16.87	-0.01	-0.29%
Cyberark Software Ltd.	CYBR	493.62	-1.88	+0.91%
Disney	DIS	103.49	+.10	-1.71%
Dominion Resources Inc.	D	57.71	+.08	+0.14%
Dte Energy Co.	DTE	127.18	+.68	+0.54%
Ecopetrol S.A.	EC	9.87	+.06	+0.61%
Emerson Radio Inc.	ELY	286.62	+0.28	-0.31%
Equifax Inc.	EFX	213.79	-2.18	+0.51%
Expedia Group Inc.	EXPE	207.62	-0.52	+0.25%
Exxon Mobil	XOM	114.77	+.26	+0.71%
Fedex Corp.	FDX	275.83	+1.66	-0.31%
Flanigan s Enterprises Inc.	BDL	32.00	+0.78	+0.71%
Ford Motor	F	13.19	+.08	+0.61%
Ford Motor Co.	F	13.19	+.08	+0.61%
GE Aerospace	GE	296.62	+2.12	+0.71%
GEO Grp	GEO	19.58	-0.02	+0.26%
Gamestop Corp.	GME	21.82	+.07	+0.71%
General Motors Co.	GM	73.81	+.09	+0.71%
Genuine Parts Co.	GPC	124.61	+.09	+0.71%
Gilead Sciences Inc.	GILD	124.61	+.09	+0.71%
Goldman Sachs Group Inc., The	GS	1,047.00	+1.00	+0.71%
Halliburton Co.	HAL	23.62	+.04	+0.71%
Hanesbrands Inc.	HBI	5.99	-0.02	-0.71%
Home Depot	HD	355.47	+4.40	-0.71%
Honda Motor Co. Ltd.	HMC	31.39	+.38	+0.71%
Hillenbrand Inc.	HNI	14.86	-0.07	+0.71%
Intel Corp.	INTC	36.61	+.96	+0.71%
Int Business Machines Corp.	IBM	303.31	+2.31	+0.71%
Int Flavors & Fragrances S.A.	IFF	67.71	+.48	+0.71%
JPMorgan Chase & Co.	JPM	307.64	+4.84	+0.71%
Johnson & Johnson	JNJ	207.58	+.98	+0.71%
Johnson Controls International PLC	JCI	119.28	+1.66	+0.71%
KB Home	KBH	64.78	+1.20	-1.71%
Lennar Corp.	LEN	121.26	+.20	+0.71%
Lovesitaland Industries NV	LYB	46.62	+1.49	+0.71%
Macy's Inc.	M	21.77	+.08	+0.71%
Marcus & Millichap Inc.	MMI	29.61	+.03	+0.71%
MacTec Inc.	MTZ	219.47	+4.90	+0.71%
McDonald's Corp.	MCD	312.46	+1.86	+0.71%
Merck & Co. Inc.	MRK	104.53	-1.66	+0.71%
Meta Platforms Inc.	META	633.61	-2.61	+0.71%
Microsoft Corp.	MSFT	485.30	+4.51	+0.71%
Mitsubishi UFJ Fin Grp Inc.	MUFG	15.81	+.16	+0.71%
Motorola Solutions Inc.	MSI	393.56	-0.91	+0.71%
Nat Health Investors REIT	NHI	85.00	-0.08	+0.71%
Nabors Industries Ltd.	NBR	49.80	-0.48	+0.71%
National Beverage Corp.	FIZZ	31.46	+.32	+0.71%
Netflix Inc.	NFLX	105.14	+1.74	+0.71%
Nextera Energy Inc.	NEE	89.34	+.71	+0.71%
Novartis AG	NVS	130.44	+.94	+0.71%
Nucor Corp.	NUE	189.00	+.00	+0.71%
Nvidia Corp.	NVDA	189.00	+.00	+0.71%
Occidental Petroleum Corp.	OXY	44.28	+.16	+0.71%
Oracle Corp.	ORCL	204.96	+7.58	+0.71%
Pattiams Medical Group Inc.	MD	34.45	-0.09	+0.71%
Pentair PLC	PNR	108.08	+.96	+0.71%
PepsiCo	PEP	147.98	+1.87	+0.71%
PetMed Express, Inc.	PETS	1.91	+.04	+0.71%
Petroleo Brasileiro S.A.	PBR	15.77	+.04	+0.71%
Pizza Pizza Royalty Corp.	PZA	10.71	-0.79	+0.71%
Ryder System Inc.	R	170.49	+.77	+0.71%
SFL Corp.	SFL	8.15	-0.06	+0.71%
SPOTIFY TECHNOLOGY S.A.	SPOT	580.99	+7.28	+0.71%
Sanger Thermodynamics PLC	SGC	2.65	+.03	+0.71%
Sanofi-Aventis ADR	SNY	50.47	+0.08	+0.71%
Stellantis N.V.	STLA	10.92	-0.02	+0.71%
TE Connectivity PLC	TEL	224.73	+2.47	+0.71%
Trane Technologies PLC	TT	419.84	+.92	+0.71%
Walmart	WMT	109.10	+0.10	+0.71%
Western Digital Corp.	WDC	197.74	+2.23	+0.71%
Weyerhaeuser Co.	WY	24.11	+.03	+0.71%
Wiley Jobn & Sons Inc.	WLY	36.31	-0.06	+0.71%
Winnebago Industries Inc.	WGO	38.44	+.19	+0.71%
XPLR Infrastructure LP	XIFR	5.55	+.17	+0.71%
Xcel Energy Inc.	XEL	81.20	+.66	+0.71%
Xenia Hotels & Resorts Inc.	XHR	14.00	-0.01	+0.71%
Xerox	XRX	9.85	-0.08	+0.71%
Yum Brands	YUM	150.80	-0.08	+0.71%
Zoetis Inc.	ZTS	127.80	-0.38	+0.71%
Zoom Communications Inc.	ZM	84.43	+.89	+0.71%

From: Micah Rothkopf
To: Hart, Grace (Aging)
Subject: RE: HCBS Aging Records
Date: Tuesday, November 18, 2025 1:57:14 PM
Attachments: image001.png

Grace,

Here is an NDSC video on protecting Medicaid and a video from Mother Jones on two podcasters who receive Medicaid. Unfortunately, we do not have official transcripts for the videos but I used a free online transcription service and pasted them below.

NDSC:
https://youtu.be/n_FkzDLW0dk?si=ptmh1yyEMFWCPphf

Mother Jones:
https://youtu.be/X6bulkw9YU0

NDSC Video Transcript:
[Music] Hi, my name is Andrean and I live in Maryland. My name is Taran. I'm from New Jersey and I have a 5-year-old daughter with Down syndrome.
My name is Alice from Ohio. I have daughter as well. Hi, my name is Deanda Frell and this is my daughter Taylor Pearson and we are here in Brandon, Mississippi. Hi, I'm Nancy from New Jersey and this is a beautiful daughter, your my beautiful daughter named J A B Y Gabby.
Hi, I'm Hannah. I'm from Atlanta. Hey, my name's Shay Landry. This is my daughter, Harper Landry. Hi, my name is Megan Doulski. I am 27 years old and I live in Pittsburgh, Pennsylvania, Pennsylvania.
My name is Kyle Stein. I live in Deuke, Iowa. Hi, I'm Becky and this is my four-year-old daughter, Nia. We are from Kansas. Hi.
Go.
You saying hi? Hi. That is Taylor. And I am Tara. I am Taylor's mom. Hi, I'm Kathleen. And what's your name?
Sam.
Hi, this is my daughter, Viva, and we're from Texas. Hi, my name is Kate Shoulders. I am from Kentucky and I have a three-year-old daughter with both Down syndrome and Hersbrungs.
um Medicaid has played a huge role in ensuring her um success and the level at which she is currently thriving. One of the um ways for me to manage my jobs is by using job coaches and I use my medication to pay them. Medic provides job support.
I had thought I didn't have to worry so much about Medicaid, but then I realized and it

was explained to me that Medicaid actually partially funded the early intervention that my daughter benefited from until she was 3 years old. B.
Medicaid has helped us pay for heart surgeries for Taylor as it has helped so many other children just like her with Down syndrome. It was really important to us that she get Medicaid because Gabby takes some really expensive medicine. Medicaid provides me with transportation through my PCA to live an almost independent life. We have used uh her Medicaid uh not only for her therapies that she gets on a weekly basis, but we also have kind of a unique experience in that we had to use her Medicaid for when she was diagnosed with leukemia.
Medicaid is super important because it's a part of our life. I work and pay for my health care, but Medicaid pays for my excess transportation and my medic. I like to work and be with my friends. Taylor lived at home with me until he was about 20 and then we started with a waiver home group home and now he's in a host home setting living as independently as possible and uh that's really been the best fit for him. We have good insurance but the co-pays are high and without the medical covering the co-pays we would never have been able to afford all the therapy that he's gotten. The reality is is that Medicaid helps a variety of people just like Taylor, people with disabilities, so that they're able to stay in their communities through services that are provided through Medicaid waiverss. Um, without her Medicaid, we would have been financially devastated.
Don't cut Medicaid, please. We depend on it for doctor appointments, class program, provider services, therapies for my daughter. Since I cannot get a full-time job with health benefits, I can't afford any medical services on my income. Please protect Medicaid funding.
M.
So, I'm hoping that we can continue to support Medicaid and its services um to help support the most vulnerable individuals like Taylor.
I am valuable. Invest in me.
Yay. Thank you.
[Music]

Mother Jones Transcript:
Babe. Hey, babe. Are you terrified?
To be honest, I'm scared as hell.
I saw this clip earlier this year, and the two hosts were talking about Trump's big, beautiful bill as Congress was debating cutting $1 trillion for Medicaid.
We're making some common sense reforms to Medicaid to eliminate waste, fraud, and abuse.
What we're doing is strengthening the program. We're reducing fraud, waste, and abuse

that is rampant in Medicaid.
A lot of people with a disability are going to feel scared of what's going to happen next.
Audrey and her boyfriend Jeremy both have Down syndrome and rely on Medicaid to live and work independently. And Jeremy started crying at this moment because they were talking about how the cuts to Medicaid might affect services that disabled people like them rely on.
Now, I just so happened to be a new mom to a baby with Down syndrome. Good job.
Oh, look at you. Okay, let's get your arms up, though. And he gets federally funded weekly occupational and physical therapy services. So, Medicaid will probably become a huge part of our lives as he gets older, too. But this moment reached a lot of other people, and it did go kind of viral.
Joining me now, Audrey Presby and Jeremy Frasier, hosts of the Audrey and Jeremy Show.
Audrey and Jeremy both went to DC to make a case for Medicaid and other fally funded health programs. We need these programs to live.
We are your neighbors, co-workers, and friends.
We have voices, and we need you to hear our voices in our side about why we should keep Medicaid.
Despite protests from disabled people, the bill passed in July, and I want to understand what effect these cuts could have on the 15 million disabled people in America who use Medicaid. So, I went and I spent the day with Audrey and Jeremy to see some of the different ways that Medicaid impacts their daily lives.
Okay. Getting double mic today.
Good deal. Good deal.
Bones off. Silence.
My name is Karolina Elas and I am executive producer of the Audrey and Jeremy Show and I'm part of their support staff uh working with them to, you know, be a better public speaker and how to learn how to make a podcast.
And our next episode is with Amy Newell.
Remember the people, the audience doesn't know her. You guys know her. So when you're like, "Hey, this is Amy Newfeld. She's a therapist. She's she's the mom to one of our friends, Jordan.
He has Down syndrome, too." And they're both super cool people.
Audrey and Jeremy payar Carolina out of a budget provided for by Medicaid. Now, this is money that in the past would have gone toward things like institutionalizing disabled people, which is what families were told to do.
But since the disability rights movement decades ago, there are now way more choices about how to use that money. how I am so thankful my support staff is here for me to help help me to have more independence.

These are called home and community based services and this program really enables people like Audrey and Jeremy to live in their community. Uh they're able to use these Medicaid funds for helpers who teach cooking and cleaning money management so they can live more independently and be part of their community.
And in Southern California, being in the community looks like this. What are we doing this morning?
Good. I'm going. Come on.
Say, "Oh, look at that. Some smiles, huh?
Look at We got boyfriend, girlfriend paddling today." For instance, a physical therapy or in occupational therapy. These are all very expensive services, by the way, that Jeremy is able to do with surfing.
Look at you go, Jay. Look at you go, Jay.
He's found all the things that surfing does is it helps his core strength. It helps his mental state and all of these things when they are out and about and they're doing all the things that everybody else does, karate lessons, art classes, going out to the beach and and being part of the community, we see better outcomes not only for the individuals, but for the people that work with them. It brings jobs to lots of people. This is the America we want to live in. One, two, three.
My support staff, her name is Sarah.
We love doing together that's so good.
All the support staff you just saw are partially paid for out of optional programs funded by Medicaid. So, they are at risk of being reduced or cut entirely. The big beautiful bill is going to be rolling out in stages. So, we don't yet know actually how this is going to look or how these programs will be affected until the states decide how to make up for these cuts.
I can't emphasize enough how important Medicaid is for all of these services.
Without Medicaid dollars, it is going to greatly impact everybody's ability in this program to be able to continue to be in it.
I was very emotional on the podcast.
It's because my my friends and myself about not just me but others. What if they will cut it? And it's going to be hard for everyone to see what's going to happen next. If they do cut it, that's the community will not be the same.
You just took the voice out of my mouth.
You are legally that good. Tried to hold it in until I did.
Wow. Powerful stuff.
Yeah. While I was with Audrey and Jeremy, I was thinking a lot about my son and how happy I would be if his life ended up looking like theirs when he's an adult.
Good job. Oh. Oh.
So before I left them for the day, I wanted to ask one more question.

What do you hope for people like my son?
Keep loving him. Have a future is bright for him. He is gonna have a successful life and he's gonna learn in different ways and see what's what's capable for

Micah Rothkopf
POLICY & ADVOCACY ASSISTANT
Pronouns: he/him/his
signature_4138698609
3825 Edwards Rd., Suite 103 | Cincinnati, OH 45209
policy@ndsccenter.org | info@ndsccenter.org | www.ndsccenter.org

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From: Hart, Grace (Aging) <Grace_Hart@aging.senate.gov>
Sent: Tuesday, November 18, 2025 12:11 PM
To: Micah Rothkopf <micah@ndsccenter.org>
Subject: Re: HCBS Aging Records

Can we be the video to possibly use for social or something and a transcript so the written version can be added to the record?

> On Nov 18, 2025, at 12:00 PM, Micah Rothkopf <micah@ndsccenter.org> wrote:
>
> Grace,
>
> I hope you are well. With regards to the Senate Aging Committee's call for HCBS stories, does the Committee want/will they accept videos of stories or only word documents/PDFs?
>
> Thank you,
>
> Micah
>
> *Micah Rothkopf*
> **POLICY & ADVOCACY ASSISTANT**
> Pronouns: he/him/his
> <image001.png>
> 3825 Edwards Rd., Suite 103 | Cincinnati, OH 45209

Submitted by David Hershel

My name is David, I am an autistic man with 37 years old and live with my parents. I participate in a Day Program that Abilis provides like Supported Typing for autistic people. This is a method that I use to communicate my thoughts and express my voice through typing on my iPad. Abilis gives training to people through a program name STeP.

My life has changed in many ways. I am able to express my thoughts, wants and ideas of things that I want to do. My level of frustrations and anxieties have diminished substantially. It has opened my door of opportunities where I can extend my wings and fly high. I have risen to the point that I am able to attend college classes like any young adult that wants to get a higher education.

You could look at my Facebook page under the name David Hershel. I am handsome fellow with an orange shirt. My presentation to sociology class tells about social problems that non-speakers face.

Karen Dungan

If not for community hab my son wouldn't be social and would have isolated all the time. Now do to these programs my son is very social and is doing amazing in his transition to work schooling. I believe that he will be able to maintain at least a part time possibly full time. I also have a sister with Down syndrome in a group home who without her dayhab would also just sit and do nothing they matter as human beings who have so much love and joy to bring to peoples lives. I'm tired of having to constantly fight for what they deserve. What kind of people would take away from them it's so sad . They should get more than what they get now to progress them and their lives. They are born this way it wasn't chosen and they are very special people who have more brains than over 1/2 of the regular people without developmental disabilities. Congress and the president should do a hell of a lot more because each and everyone has a gift that can be tapped into and make a difference if they would just give some money to help develop there special skills .
Thank you

Riley Mello, Maureen Curtin, James Mello, Jimi-James Mello

To whom it may concern,

If home-based community services are taken away, a huge number of people will be impacted. The individual with the disability, their family, and in many ways our society feel the affects. The disabled person will not disappear when you take away the services, they will become a greater burden! The disabled never did anything themselves to be in their situation! The people of a society are meant to assist one another. When that happens, folks with disabilities will have

their abilities increase. Home-based community services allow people with disabilities to feel seen. To feel enabled. And to feel more like they’re a part of society.

Please fight to keep home-based community services!

Maureen Curtin

To whom it may concern ,If home based community services are taken away ,a huge number of people are impacted .The disabled individual ,the family ,and society .The disabled person will not disappear when you take away the services ,they will become a greater burden to society .The disabled never did anything incorrect to be in their situation. As a society of humans we are meant to assist one another. These services allow these people to feel seen and be a part of society .Their abilities increase with support .

Maureen Curtin

To whom it may concern ,If home based community services are taken away ,a huge number of people are impacted .The disabled individual ,the family ,and society .The disabled person will not disappear when you take away the services ,they will become a greater burden to society .The disabled never did anything incorrect to be in their situation.As a society of humans we are meant to assist one another. These services allow these people to feel seen and be a part of society .Their abilities increase with support .

Ann Sherff

My husband and I have five adult children. Our three sons have disabilities. My husband's 84 year old sister has a disability. My husband is 81 and I am 78. Our 51 year old son Michael, 41 year old son Jonathan, and 84 year old sister Joan, live in community based apartments IRA operated by voluntary NYS OPWDD agency. Michael and Joan has lived in their apartments since 2003. Jonathan has lived in his apartment since 2014. Our 36 year old son, Matthew, who is deaf and has autism lives with us still. All four have had and still have self directed services for some or all of their supports which allow for more individualized community inclusionary opportunities.

Joan has had a number of health issues the last several years. Her apartment was designed for aging in place when the building was built. In the last few years when Joan has been hospitalized, the agency tried to "push her into" a nursing home rehab which I know would have turned into a nursing home placement for her. I advocated strongly for her and each time coming back to her own apartment, she returned to her baseline within a week. My concern is that agencies will not allow people to age in place, even when the home is accessible and has

the supports for the person. Her current residence allows her to continue to a part of her community whereas a nursing home would remove her from the community.

Michael has self directed services that supports him with community inclusion and a part time job.

Jonathan does not have self directed services now, but had them in the past. Jonathan has mental health issues along with developmental disabilities. The supports and services he gets allows him to be in the community with individualized opportunities.

Matthew who still lives with us has self directed services. He is in need of a community based opportunity similar to his brothers and aunt. Living at home with us limits his opportunities because his total depends on me for much his community based opportunities. I feel he would thrive in other ways if he had the opportunity to live in a supportive apartment such as his brothers and aunt have. He has been on the OPWDD certified residential list for housing for twenty years. This year for the first time in many years, there was an opportunity to look at two openings - one was for a shared bedroom with another man in a small room what two beds would have taken up two thirds of the space. The man already living there, did not want a roommate. The other offering was a single bedroom but the other 6 residents were elderly and/or limited skills and would have nothing in common with Matthew. That house had one van which would limit community activities to the majority going. Matthew would loose the community connections and people that he has and he very unlikely not be able to establish meaningful new connections in that setting.

As aging caregivers we have lost some of our ability to be in the community with others unless we have someone willing to work with Matthew at times when we need coverage to participate as a couple and/or alone in community activities that have value and meaning to us. We have become isolated as aging caregivers which at any point could mean for either one of us could be caring for Matthew and our spouse. I continue to advocate for and support our other family member to ensure the services they are receiving are happening and appropriate. I don't know who will step in to that when I no am able to do that.

I volunteer across systems that include mental health, family supports, independent living centers, advocacy / oversight organizations, aging, and civil rights. I have advocated throughout the lifespan of our children for them to be in and a part of our community from being in our local school when they were young and now as adults in community activities.

The ILCs have been a great resource for information and support in navigating the service systems. I have found them more knowledgable than many of the state funded OPWDD providers.

My concerns are aging in place for my family members, the opportunity to have true community based opportunities that are individually driven, our need as caregivers for respite that is affordable, available and flexible to meet out needs and not the providers needs. There is a

strong need for an appropriate community based living arrangement for Matthew due to our ages and health issues.

Jonathan Polanco

Hi my name is Jonathan Polanco and I am 19 years old. I have been typing to communicate through the FC Method (Facilitated Communication) since I was 14 years old. Before that I learned to communicate through RPM (Rapid Prompting Method) I am now able to communicate my needs and wants with minimal resistance touch on top of my shoulder and am working towards complete independence. This is very important to me because they reflect my authentic thoughts, needs, and wants instead of having to choose from a limited menu in a set program.

The agency that supports me and my method of communication is Abilis / Step Program and my school. They understand that I am intelligent and have thoughts and opinions and a yearning to learn. It has freed me and given me hope for a productive life where I can be an asset, contribute to society, and have my own choices for a better quality of life.

I would like the Special Committee on Aging and all Agencies to understand how important this Communication Bill S7792 is to our population so that we are free to use our fundamental right to communication everywhere we go. I would like the agencies that service adults to offer training and opportunities for non-verbal clients to type or spell. I would like the educators and trainers to also be educated in and understand dyspraxia and our brain and body disconnect.

Kindness and understanding of our real issue is the only true and genuine way to support us.

Please support the Communication Bill S7792.

Thank you for reading my letter.

Joseph Potts

Dear Members of the Special Committee on Aging,

Community living matters to me because: My wife and I live off of SS retirement. My son with IDD waited 18 years to get HCBS services. We had to send him to private school because Fort Worth ISD was using his special needs teacher to tutor regular kids for the TAST test while students taught my son. My son is 35 now and when he was in elementary school he was not given any type of TAST test. We spent all our savings putting my son through school and waiting for HCBS services for the 18 years. If we did not have HCBS we could now only afford beans witha no community outings. With HCBS we have money for Ryan to participate in his

community spending money, helping the economy and himself. I am old and sick and when I and his mother are gone HSBC is his only hope for any kind of life.

Maria Faralli

Our ARC is an a integral part of community with our Special needs adults.

My daughter is a major benefactor of all the Special Services they offer.

First of all, the staff is exceptional, headed by a brilliant woman, Majken Mechling.

My sweet daughter lives at home but we participate in all the outings the ARC offers. We have gone to the Eagles training camp and Phillies baseball game, just to name a few.

They also have monthly dances.

We just had a beautiful Thanksgiving feast too.

We love our ARC!!

1135

Dear Senator,

I am writing to you with a strong concern regarding the aging population in Indiana. As life expectancy increases and medical advancements allow people to live longer, the need for comprehensive home care services and healthcare for the elderly has become more urgent than ever. Meeting these needs is essential to ensure a high quality of life, dignity, and independence for older adults.

Elderly individuals often confront a variety of physical, emotional, and social challenges. Common issues include chronic health conditions (such as diabetes, heart disease, and arthritis), decreased mobility, cognitive decline, and increased vulnerability to accidents. Furthermore, many older adults feel lonely and isolated, especially if they live by themselves or are separated from family members.

Home care services offer personalized assistance for elderly individuals in the comfort of their own homes. These services may include help with daily activities (bathing, dressing, meal preparation), medication management, physical therapy, and companionship. Home care enables seniors to maintain their independence while receiving the support they need to stay safe and healthy.

Recent Medicaid changes have significantly affected elderly people receiving home care. The changes have caused the loss of health coverage, increased stress, housing instability, worry, and depression among clients. I am dedicated to advocating for these individuals and ensuring that high-quality care is delivered.

Sincerely,

Sierra E.

Convergence Home Care Services

Dear Senator,

With the demographic landscape of Indiana shifting toward an increasingly aging population, the health and well-being of older residents take on heightened importance. Access to comprehensive healthcare is indispensable for elderly individuals, as it facilitates not only the management of chronic conditions but also the preservation of independence, dignity, and overall quality of life.

Management of Chronic Conditions

A significant proportion of elderly individuals in Indiana contends with chronic health issues such as cardiovascular disease, diabetes, arthritis, and hypertension. Consistent access to medical care enables early diagnosis, effective management, and sustained treatment of these conditions. In the absence of appropriate healthcare, such conditions may deteriorate, resulting in increased hospitalization, serious complications, or even premature mortality.

Mental Health and Social Support

The elderly population faces an elevated risk of mental health challenges, including depression and anxiety, often stemming from social isolation, bereavement, or declining physical health. Healthcare providers not only deliver medical interventions but also facilitate connections to counseling, social services, and community resources, all of which are essential to comprehensive well-being.

Mitigating Financial Strain

Timely access to healthcare can prevent costly emergency department visits and hospitalizations by promoting proactive management of medical conditions. Public programs such as Medicare and Medicaid, along with state-specific initiatives in Indiana, help reduce out-of-pocket expenses and increase the affordability of healthcare for seniors.

Securing access to robust healthcare services for elderly individuals in Indiana is fundamental to their physical, emotional, and economic welfare. Such measures not only enhance individual lives but also provide crucial support to families and communities by fostering healthier, more self-reliant seniors.

Sincerely,

Sierra E.

Convergence Home Care Services

Dear Senator,

Senators play a crucial role in shaping healthcare policy, especially for vulnerable populations such as the elderly. Their influence extends from legislative action to advocacy, oversight, and collaboration with stakeholders. This letter outlines the various ways a senator can impact healthcare for older adults in the United States.

One of the most direct ways a senator can affect elderly healthcare is through legislation. Senators can propose, sponsor, or support bills aimed at improving access, affordability, and quality of healthcare for seniors. This includes laws relating to Medicare, Medicaid, long-term care, prescription drug coverage, and preventive services. By working on committees such as the Senate Committee on Health, Education, Labor, and Pensions (HELP) or the Senate Finance Committee, senators can shape the details and funding of programs that serve older adults.

Advocacy and Public Awareness

Senators have a national platform that enables them to bring attention to issues facing elderly populations. Through speeches, media outreach, and community engagement, they can highlight gaps in care, the importance of preventive medicine, and the need for reforms. Their advocacy can mobilize public support and encourage other lawmakers to prioritize senior healthcare.

Oversight and Accountability

Beyond passing laws, senators are responsible for overseeing federal agencies that administer healthcare programs for seniors, such as the Centers for Medicare & Medicaid Services (CMS). They can hold hearings, request reports, and investigate issues such as fraud, abuse, or inefficiencies in elder care programs. This ensures that resources are used effectively and that seniors receive the benefits they deserve.

Securing Funding and Resources

Federal funding decisions often originate in the Senate. Senators can advocate for increased funding for senior health programs, local clinics, research on aging-related diseases, and initiatives aimed at supporting rural and underserved elderly populations.

I have witnessed the worry, stress, and heartbreak that clients and seniors have been experiencing. I continue to advocate for them and be a voice in the community. This letter is to emphasize how critical your support is. Senators have multiple avenues to impact healthcare for the elderly, from crafting legislation and securing funding to raising awareness and providing constituent services.

Your leadership is essential to ensuring that America's seniors receive high-quality, affordable, and accessible healthcare.

Sincerely,

Sierra E.

Convergence Home Care Services

Ruth McMillion

I have worked with individuals with developmental delays for 33 years. I have seen so much growth with various individuals. They have the same hopes and dreams that we all have, having a job, their own home and a partner. They have told me that they want to live in an apartment, so they don't have to mow the grass. Or they want to live in a house with a porch so they can sit outside on the porch swing and listen to the birds. They want to work to make money to buy and do things they enjoy. They want to work like their dad, because they're a man like their dad.

I have seen the positive impact they have in our community. When I was younger people with developmental delays were kept out of sight. If I seen someone with differences, it made me uncomfortable. Today the community has changed, they are open and kind. I have taken individuals to restaurants where the young waitress was afraid of my guys. But we kept going back and every time she became more at ease. She would see them in various places and always greet them with a smile. They are consumers of goods and services that help build our community.

I believe that everyone has a place in the community, it may not be everywhere, but they can have it somewhere. It should be your mission to help not only people with development delays, but everyone to grow and have the chance to do and be better in life.

ADULT DAY | Tammy's Story

Tammy unpacked her lunch bag and put her ravioli in the microwave. She set the timer, and while she waited, she put in a load of laundry. These are just a few of the ways Tammy has become more independent thanks to the **Easterseals Crossroads Adult Day** program.

"I have seen her confidence skyrocket," says Breann Riley, Activity Lead and DSP.

For more than two decades, Tammy has been attending Easterseals Crossroads Adult Day program at the south location. The program is for adults with disabilities, and it also gives family members and caregivers some respite. However, the program is not an adult daycare service.

"A lot of people have that misconception, that it's daycare for adults," Breann says. "That's far from the truth. We do so many things to make their lives meaningful. They volunteer in the community, they go places, they learn new skills, improve social skills, and we even have clubs for things like photography, cooking, and reading."

Tammy has taken full advantage of her time in the program, especially when it comes to serving in the community. For two years she's been volunteering at Calvary Lutheran working with Kindergartners, helping with learning activities and play time. Tammy also took an online training course to become a certified volunteer at Nine Lives Cat Cafe.

The Adult Day program is more than just a place to be. It's helping people, like Tammy, find true independence.



ADULT DAY

64,982
Hours of Adult Day and Recreation Therapy

147
Volunteer hours completed by participants

323
Trips with opportunities to become active members of their community

Tammy's Favorites

Being at Easterseals Crossroads with her friends and doing diamond dots and coloring pictures.

Feeding the kittens at Nine Lives Cat Cafe.

Doing activity books with the students at Calvary Lutheran.

Going to Dave & Busters to play games and win prizes.