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FROM INFANCY TO AGING: THE EFFECTS OF CAREGIVING ACROSS THE LIFESPAN

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FROM INFANCY TO AGING: THE EFFECTS OF CAREGIVING ACROSS THE LIFESPAN

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

The Committee met, pursuant to notice, at 10:00 a.m., at Vintage Senior Services, 421 North Highland Avenue, Pittsburgh, Pennsylvania, Hon. Robert P. Casey, Jr., Chairman of the Committee, presiding.

Present: Senator Casey

OPENING STATEMENT OF SENATOR ROBERT P. CASEY, JR., CHAIRMAN

The CHAIRMAN. Welcome, everyone. This hearing of the Senate Special Committee on Aging, this is a field hearing and the hearing will come to order. I want to start by thanking our host today, Vintage Center for Active Adults, and Heather—where's Heather? Maybe she's in the other room.

Heather, thanks for making this possible, and I know your whole team is part of that, so we're grateful for your hospitality to talk about the critical issues we're here to discuss, and I'm grateful to be with our witnesses, each of whom I'll introduce in a moment.

The title of today's hearing is ″From Infancy to Aging: The Effects of Caregiving Across the Lifespan.″ Today, we'll focus on the caregiving needs for children, for aging adults, for family members with disabilities, and for the needs of those who care for and support them.

Over the past 60 years, caring for our loved ones has become more and more difficult, with many family members taking on caregiving roles, in addition to their other family and work responsibilities. Tens and tens of millions of Americans work as caregivers. By one estimate, there are more than 1.6 million here in Pennsylvania, serving as caregivers.

Some care for young children, some care for aging parents and family members with disabilities, and some care for all three. A large portion of adults are now in what we know as the ″sandwich generation.″ They're providing care for multiple family members, often caring for children, while also caring for an aging parent or a family member with a disability.

These increased care needs are putting significant stress on families, resulting in lost wages, and decreased financial stability. For example, and this obviously we'll hear lot, many more examples today, but Linda Orndoff, who's with us today, is a caregiver, and in her testimony, she discusses these stresses, and that might be an understatement, pointing out that she is currently making the same hourly wage as a caregiver that she made as a quality assurance assistant in the late 1980's and early 1990's.

However, most caregivers are not paid for their work and often don't have a choice in whether or not to provide care. Caregiving can be a role that provides great joy and great sorrow, sometimes in the same day, or even in the same hour. Almost universally, however, caregivers verge on exhaustion, often putting their own personal and healthcare needs aside—with finding childcare, and parents, especially women, often leave the workforce to care for their children, their spouses, or their aging parents.

To address caregiving needs, we must invest in childcare. When I say we, I mean the federal government, should invest more in childcare to ensure that there are enough providers, and that families have access to affordable, quality childcare.

We also must address the needs of families with aging parents and other family members who may have mobility, vision, hearing, and cognitive needs, and we must ensure that families of the over 61 million people with disabilities have the services and supports that they need to be full members of our society, and we must provide working Americans with paid sick leave, and family and medical leave, to be available to provide care to family members when needed.

We must continue to invest in programs like home and community-based services, so-called HCBS, to make it possible for aging Americans and people with disabilities to receive care in their homes and in the community. A common theme that many families raise when talking about care is the inconsistency of care and the turnover of staff, whether they be childcare providers or home health staff.

Today's witnesses shine a spotlight on the value and the challenge of the unpaid work of family caregivers. We need to do more to acknowledge them, to lift them up, to provide families with the resources they need to care for each other and to care for themselves, and Isaac Bashevis Singer's short story, Gimpel the Fool, he writes, "God gives us burdens, also shoulders." Some shoulders are strong, others have been worn down. We need to do more, and again, I'll say it, the federal government needs to do more to support those providing care as well as those needing care. As a country, we can provide supports so that all of our shoulders can provide the care our loved ones need.

Today, we'll hear from five witnesses who will discuss their experiences receiving care and as caregivers. I look forward to their stories about the challenges they face, the stressors in their lives, as well as the successes they have experienced in their caregiving roles.

Let me start by introducing our witnesses. Our first witness is Heather Tomko. Heather is the outreach coordinator for the National Center on Family Support at the University of Pittsburgh and lives in Whitehall Borough. Heather, thanks for being here with us, and Heather also serves as the connection between research grants and the larger family caregiving community. She also has a website that comments on daily life as well as disability issues. Heather, great to be with you and thanks for being with us.

Ms. TOMKO. Thank you.

The CHAIRMAN. Our second witness is Tara McGuinness. Tara is founder and executive director of the New Practice Lab at New America. She also served in the Obama Administration as a senior advisor in the Office of Management and Budget, addressing healthcare and family economic issues. She specializes in management, data practices and technology to address family and community policies. Thanks so much, Tara, for being with us.

Our third witness is Delilah Picart. Delilah is an actress and educator who cares for her mother with dementia, and her brother who has fragile X syndrome and autism. She also has an 18-year-old daughter, and she lives here in Pittsburgh. Delilah, thank you for being with us today.

Our fourth witness is Victoria Snyder. Victoria is also a resident of Allegheny County, Leet Township, and is a single mother and small business owner who cares for her six-year-old son with autism. She's been involved in caregiving for both her mother and her late grandmother Victoria, thank you for being with us today as well.

Our fifth and final witness, I made reference to in my opening, Linda Orndoff. Linda is a homecare worker who cares for her 89-year-old deaf mother with dementia. In addition to caring for her mother, she serves as a guardian for her twenty-seven-year-old grandson who has autism along with other health conditions. She lives in Cole Center, Washington County. We're grateful to have you here.

Why don't we start with our witness testimonies. Every witness will provide testimony, and then I'll start a round of questions, so Heather Tomko, we'll start with you. Thank you.

STATEMENT OF HEATHER TOMKO, OUTREACH COORDINATOR, NATIONAL RESEARCH AND REHABILITATION TRAINING CENTER ON FAMILY SUPPORT, UNIVERSITY OF PITTSBURGH, WHITEHALL BOROUGH, PENNSYLVANIA

Ms. TOMKO. Thank you so much for having me here today, Chairman Casey. My name is Heather. I am 35 years old and grew up here in Pittsburgh. I went to both Carnegie Mellon University and the University of Pittsburgh, and I work there now at the National Center for Family Support where I serve as liaison between academia and the larger area community.

As you can see, I have a disability. I have spinal muscular atrophy, which is a neuromuscular progressive disease, so what that means for me is I've never been able to walk. I've used a wheelchair for as long as I can remember, and I need help with the things that most people just take for granted every day, so getting in and out of bed, using the bathroom, taking a shower, even heating a meal prepared. These are things that I cannot do independently.

For the entirety of my childhood. I got that help through my parents who were my unpaid family caregivers and helped me with those basic daily needs, but when I went to Carnegie Mellon University, I wanted to live in the dorms. Obviously, my parents couldn't come with me there, so that was my first foray into paid care giving and having personal care attendants.

While I was adjusting to living away from home for the first time, I was also addressed into teaching new people how to do what are pretty intimate tasks for me, and as you heard in the intro, there was a lot of turnover and a lot of instability, so a while I did go through an agency to help me find and schedule those PCAs, and that when one of them had to call off, when the agency would try to find a replacement, the responsibility was on me to make sure that they found one because I was the one without care if they weren't able to.

When I was studying for an exam the next morning, or finishing my homework or assignment, I might also be calling the agency every hour to see if they had found a replacement yet, or making an 11:00 p.m. call home to my parents asking my mom to come stay the night at the dorms so that I was able to go to class the next day and also get much needed sleep.

This instability was a large part of the reason that I moved home after college and that I still live with my parents today. We have a patchwork system of unpaid care through my parents and unpaid caregiver, and my sister shares the same disability that I do and lives at home with me, so we are constantly figuring out logistics of two adults trying to live their lives and deal with the uncertainty of when a caregiver has to call off, and we all have to figure out our schedule for the next day and how to make just the basics of a day happen, and these are my experiences, but these are something that I see shared every day in my role as the outreach coordinator. No matter what webinar or program I'm holding, I get multiple questions of how family members can find paid caregivers to help them better support their loved ones, because right now—paid and unpaid caregivers as two separate entities. They're really existing on a spectrum. Family members are looking for paid caregivers to help them support their loved ones so that these family members can also take care of themselves and their needs.

My parents are aging. I'm 35. I know that they can only provide the support that they are right now for a few more years, and I really fear where that leaves me to have a vibrant life, and work, have friends, and hobbies, and living up in a nursing home is a very real fear of mine that I grapple with every day.

This is something that has been bad always, but after the pandemic, when other companies reacted by raising wages to make up for the loss of workers, as you have mentioned, caregivers have not seen that increase in wages, so I am struggling with not knowing if a replacement caregiver will be found when mother's gone off or if I'll have to deal with the mental and physical strain of trying to train new caregivers, daily or weekly, just to meet my basic needs.

We need to see increased wages for paid caregivers to make this into a viable career choice and not one that you have shifts more in the fly, so I urge you, Chairman Casey, and the Committee, and the federal government to invest in the paid caregivers to make this a viable career option so that people like me can live our lives to the fullest. Thank you so much.

The CHAIRMAN. Heather, thanks so much, and thanks for sharing so much of your own personal experience, and we're going to get further into it with some questions.

We'll turn next to Tara. Thank you.

STATEMENT OF TARA DAWSON MCGUINNESS, EXECUTIVE DIRECTOR, THE NEW PRACTICE LAB AT NEW AMERICA, WASHINGTON, DC

Ms. MCGUINNESS. Thank you, Chairman Casey.

″We resonate with many here. The youngest grandson is autistic. You know what I'm saying? I can't take him everywhere because I have to hold his hand 24/7, even walking down the street. I can't release his hand because he'll wander off.″

These are the words of Walter, a grandfather and sole caregiver of his two grandchildren in Philadelphia. He is one of the number of families who are part of our Thriving Families Project, an ongoing effort in Pennsylvania and other states to really listen to families, as we're doing today, and get a whole picture of what helps them thrive.

Unfortunately, at a policy level, what we're doing here today is very rare. We don't often center on the family experience. We approach these phases of life as separate challenges; early education, childcare, policy, disability. However, as you're hearing from Heather and others, care shows up all at once in a family. If we're raising young children, we might also be caregiving for our parents. If we are grandparents, we might, like Walter, be unexpectedly raising our grandchildren.

In Pennsylvania, that is true for more than 76,000 grandparents who live with children or whom they're responsible. Nearly half of these grandparents are in the workforce themselves. Other families live with challenges that are different. I know this to be true. I have young kids and aging parents. Like 20 million American families, mine cares for someone with disabilities.

Today in the U.S. though, we make it way too hard at all ends of the spectrum. First, to start and raise a family. Household costs go up with a birth of a child, right at the same time that wages go down. About 130,000 new children are born in Pennsylvania every year, and folks are starting to raise a family.

When a new baby is born, parents are on their own to figure out how to manage care because there is no paid family medical leave. Having a child is just the beginning. Being able to make a living and raise kids is hard because most communities don't start school until kids are five. That's true for 800,000 working parents here in Pennsylvania with kids under the age five, and the majority of them need care.

This care comes at a very steep cost. Last year, the average Pennsylvanian family paid about $14,000 a year for center-based care. This of course varies widely across the State from around $8,000 a year to nearly $20,000 in other places. Here in Allegheny County, the average for a year of care is around $13,700.

Affordability is just one piece of the equation. Childcare, staffing shortages mean there's simply not enough providers to meet families' needs.

In Pittsburgh, childcare workers make on average $13 and 42 cents per hour, which is about $28,000 of an annual salary. For a childcare worker to have a modest living standard and raise their own children, they would need, on average, $40,000 more a year than they're making. Wages are far too low, as we've discussed, and this has huge effects because often, these jobs are done by women and women of color, and so, the rippling effects of low wages spreads out.

It isn't just families with young kids, families taking care of a loved one with a disability as 14 percent of Pennsylvanians are while trying to earn a living have challenges, and as we age, you know, modern science has allowed us to live longer and more than any point in history, but that means we have new care needs. Pennsylvania is home to, generally, 3.4 million older adults. To meet their needs, Pennsylvania will have to recruit 275,000 new care workers in the next six years, and this turnover rate here is around 64 percent.

We have experienced dramatic shifts in how we live. In just a few generations, we moved from a typical family, having one person at home doing caregiving, to a situation where most American children are raised by two working parents, but we failed to make changes that would create infrastructure to meet these needs. This care fix isn't an impossible dream.

Nearly all countries in the world have the things we're being discussed, and even 13 states across America have paid family medical leave. Globally, our partners all have investments much greater than ours in high quality early education. Making caregiving a legislative priority need not be partisan. 82 percent of voters support making it easier for people to care for the people they love.

Thich Nhat Hanh said, ″Caring is the bridge that connects us to one another.″ Today, we are in deep need of more connection and policies that enable us to do and care for those we love. I want to thank Senator Casey and the Aging Care Committee. This hearing is a very important step for the federal policies to anchor into the voices of folks like those in the room, and to answer what families are universally asking for; policies that support them through the moments of all their lives that require care.

Thank you, Senator Casey.

The CHAIRMAN. Tara, thanks so much, and I was highlighting a lot of those numbers as you were giving the numbers we need to remember when we're formulating policy. We'll try to get into them a little bit later.

Delilah.

STATEMENT OF DELILAH PICART, ACTRESS, PITTSBURGH, PENNSYLVANIA

Ms. PICART. Thank you.

Good morning, Chairman Casey. My name is Delilah Picart. I'm from New York City, yet I've called Pittsburgh, Pennsylvania, my home for 20 years. My professional career as a working local actress has allowed me to appear in films and commercials, but currently I have a job I didn't apply for, and I can't quit.

I am a caregiver to my brother and mother. I moved them here from East Harlem in April 2023, when it became obvious that mom couldn't take care of herself or my brother anymore. My brother, Eric, has fragile X syndrome and severe autism. I always anticipated I'd have to take care of him. My mother, Vivian has moderate dementia. I didn't think I would be taking care of her. My father, Enrique died in 2011 from complications of Alzheimer's disease.

I have a complicated relationship with my mother. She believed in tough love parenting, and with therapy I realized we are fundamentally different people, so for my own mental health, I would go and visit my mother and brother three times a year, never for more than five days. My mother called me one evening in July 2022. She said she was having a hard time, and she wanted to get a power of attorney document.

I decided to visit my mother and brother once a month for a three-day weekend, and over the next nine months, I saw my mother ignore and neglect my brother. She would forget appointments. She would forget to feed my brother. She no longer cooked. Her refrigerator was packed with containers of food wrapped in plastic bags. She had bags of liquefied lettuce, molded vegetables, old bags of bacon.

It was very obvious to me that Vivian had dementia. Eric was being neglected and they needed to move closer to me. I asked my family members to help pack her up to move with a target date of April. As a caregiver to two individuals with very specific different needs, I am exhausted.

I'm mentally, emotionally, physically, and psychologically tired. I don't have the luxury or the monetary fluidity to take a break. As their primary caregiver, I manage their daily care, which includes pill management, preparing all meals, laundry, garbage disposal, transportation, dressing, coordinating, and scheduling of companions, cleaning the apartment, grocery shopping as needed, scheduling doctor's appointments, personal grooming appointments, bathing reminders.

My family lives in a two-bedroom, two-bathroom apartment, four blocks away from my house in Shadyside. It was decided very quickly that they could not move in with me and my fiance, Todd. Mom, had a very hard time adjusting for the first six months. She was aggressive. After she threw a computer tablet at me and missed, I got her on meds that have calmed her down.

My brother was very happy with the move. He was getting three meals a day and healthy snacks. I introduced him to red peppers, and avocado toast, and lemonade. I could tell he finally felt validated and acknowledged. Eric was receiving services in New York City, but he was ineligible in Pennsylvania until he had legal residency for six months. Even then, I had to show medical records for over 30 years ago, describing and diagnosing his dual disability.

By January of this year, he had a very helpful case worker. His individualized support plan declared him an emergency case because he was living with his mother who was diagnosed with dementia. Still, it took eight months before he received emergency waivers. Recently, his behavior has changed, and now he leaves his apartment and arrives at my house to sit on my porch by 5:00 a.m. I have adapted. I love my brother immensely.

I have a good life. I'm fortunate. I have a therapist, a support group, and a weekly session with a trainer at a gym. Both Todd and my daughter help, yet, I've had low points. I've watched the

Twin Towers fall. I've had four car accidents. I've had a stalker terrorize me, and I've had my father go missing for 34 days. This is the most challenging event I have ever experienced.

When I'm asked, "How are you?" I give a very bland reply, "I'm fine. Everything's good." With my close friends and a few family members, I'm honest. I'm sad, or angry, or good in this moment. I'm tissue paper thin. I'm spent. I'm struggling. I just can't today.

In an ideal world, a hotline would be available to provide urgent support. An example, cleaning services, laundry services, meal delivery, companionship. Medicare, and Medicaid would easily transfer information across states. A caregiver would be granted a parking pass to go into the disabled parking spots at the grocery store and hospitals, et cetera.

State programs could provide college credit to graduate students in the social services department and have said students provide hands-on companion care to people with intellectual developmental disabilities. Supplemental income would be provided to caregivers with more than one individual in their care and would include people with all forms of dementia and severe autism, not exclusively for people who are incapacitated and home bound. Service agencies would receive more money to have more staff and more respite housing, so emergency means immediately, not eight months.

Thank you for your time and your attention, Senator.

The CHAIRMAN. Delilah, thank you for sharing your personal story, and I like to think I have a challenging job, but nothing compares to what you and others are living with every day, so we're grateful you're willing to share it in a public setting to help us better understand what the challenges are, and to then by definition, challenge us to find better solutions.

Victoria.

STATEMENT OF VICTORIA SNYDER, SELF-CARE SENORITA AND DIRECTOR OF STRATEGIC INITIATIVES, RIVERSIDE CENTER FOR INNOVATION, LEET TOWNSHIP, PENNSYLVANIA

Ms. SNYDER. Good morning. I'm Victoria Snyder, and I'm a single mom to a terrific son, Braxton, who's about to start first grade. We live here in the Pittsburgh area and I am a proud member of MomsRising.

I first want to start and say thank you to Senator Casey for organizing this hearing and for all you do to improve the support for caregivers. It truly means a world to moms like me, and I appreciate the chance to share my family's story and many families that are similar to mine. I'm a sandwich generation mom who has sole physical and financial responsibility for my son. Over the past few years, I've also provided care for my mother and for my late grandmother.

Juggling care for a young child and aging relative has become an enormous challenge as we've heard, financially and emotionally. These challenges are much worse because lawmakers have failed to ensure working people can access paid leave, and quality, affordable childcare, and elder care.

The beginning of the pandemic was especially hard for our family. During Covid, Braxton was diagnosed with being on the autism spectrum. He needed occupational speech and behavioral therapy each week, and I don't know if you've ever had to do Zoom with a two-year-old, but it's not exactly an enjoyable process. My grandmother got Covid and spent months going in and out of the hospital. My mom also was injured during that time, and she spent some time in the hospital.

I had no money coming in as I had lost my job when Covid had happened, and couldn't look for a job because I had no one to watch Braxton because childcare was closed. It was an extremely scary time, filled with a lot of worries about what tomorrow would bring, because of the unknown and even flexibility with my own schedule and Braxton's needs, I started a business, Self-Care Senorita, and worked as a small business coach and DEI consultant. During all this, my biggest fear was always what would happen if I got Covid, or worse, an injury that would cause me to not be able to work. I couldn't get sick. I couldn't get hurt. What if I did? I wouldn't be able to work, and then what would happen with my family? Destitution was always a knock at the door. Those what-ifs still haunt me every day.

Thankfully, Braxton's preschool finally reopened, and having childcare again was a relief and allowed me to work more hours, but it also cost me $800 a month, a big portion of my take home pay, and that was being discounted as a low-income single parent. Last year, Braxton started kindergarten, and I took a full-time job so he could have medical benefits. I'm still struggling with childcare outside of school hours. At first, I tried enrolling him in an afterschool program, but that program is expensive and ultimately, we just couldn't afford it.

Instead, I interrupt my workday each afternoon to pick him up from school, which is stressful. In order to get my work hours in, I log in before school, I take him to school. I pause, get him dressed, get him ready, take him to school, drop him off. Pause, and work again to drive to work. Go to work, work, leave there to go get him from school, and then come home and work most evenings.

It's exhausting trying to manage it all. Even today, there were seven steps to my morning. I had to take my son to my work for a coworker to take him to childcare, his summer camp, because it didn't open until 9:30, so even being able to do really amazing things like this, there's still difficulty in access to childcare.

My new job does also does not provide paid leave. I still worry about what would happen if my mother or my son were to get sick. I have to save all my paid time off for a what-if scenario instead of using it for a vacation time with family or even for my own sick days.

Unfortunately, I know so many parents and caregivers can relate to these challenges. Here in Pennsylvania, about two-thirds of us do not have access to any paid leave through our employers to care for our kids ourselves or our aging loved ones. About 60 percent of us live in childcare deserts, and for kids under five, care costs nearly as much as public college tuition. These challenges have limited my income and my career opportunities, and I know so many moms who can say the same thing. When working people like me can't fully utilize our skills, that's bad for business and our overall economy.

As I've juggled these responsibilities over the years, I often feel like I'm running in a thousand directions at once. Sandwich generation caregivers like me are struggling with burnout and exhaustion. I joined MomsRising because I know the only way we'll see progress is if we raise our voices. So, I'll never stop using my voice to tell lawmakers to invest in the care infrastructure working families' need with paid leave for all, affordable, high-quality childcare, elder care, and disability care, and expanded childcare tax credit.

Senator Casey, thank you for what you do and the fight that you do for us. Thank you.

The CHAIRMAN. Victoria. Thank you for sharing your story as well, and you've given us a lot to think about on that list you provided at the end of action items. Victoria gave us a list of action items at the end of her testimony, and I think that's something that federal legislators like me ought to be cognizant of, so thank you.

Finally, Linda, we'll conclude with you.

STATEMENT OF LINDA ORNDOFF, HOMECARE WORKER, COAL CENTER, PENNSYLVANIA

Ms. ORNDOFF. Hello, Chairman Casey. My name is Linda Orndoff. I'm a homecare worker from Coal Center, PA, and I take care of my elderly mother and my oldest grandson who has autism.

I'm a participant-directed homecare worker, and this means I work directly for my participants; my mother, and my grandson, rather than through an agency. This type of care allows the participant to direct their own care and to choose who works for them. A lot of times, like in our situation, this means family members. They choose people they know and are comfortable with rather than whomever the agency sends.

Nevertheless, whether you're a participant-directed or an agency worker, doing homecare work is a big sacrifice. When I was asked to come here today to speak to you, I was told to just tell my story. I want to share what it's like to be a homecare worker, but to make you understand what a homecare worker goes through, you need to know why the situation is like it is, because of poverty, wages, and no benefits, we have a huge crisis in the homecare industry. Tens of thousands of homecare workers must depend on state and federal system programs like food stamps, Medicaid, and sometimes cash assistance just to live.

In our country, there's only one caregiver for every six people who need more care to make it possible for them to be able to remain in their homes. Without enough homecare workers, many people are being forced into nursing homes and assisted living facilities as they cannot find caregivers to keep them at home.

In 2021, the annual turnover in the care workforce was 64 percent and it has only gotten worse. It's gotten worse because most potential caregivers are unable to do this type of work when it pays so little and offers no benefits and no security. In my case, when my mother and my grandson began needing my care full-time, I had a big choice to make put; them in a home or quit my job, and I chose them.

After that, everything about my life changed. When I had to quit my job, I took a huge pay cut and suddenly I had to figure out how to live on poverty wages. I'm currently making $13.52 an hour, which is the same hourly wage I made back in the late 80's and early 90's. I could barely live on those wages then, and I certainly can't live on those poverty wages now.

When I chose to take care of my family and stop working, I no longer had health insurance, no paid sick time, no paid vacations, and no type of retirement benefits whatsoever. My mother and grandson depend on my care ten hours a day, seven days a week. My mother has polycythemia vera which is a rare blood disorder that makes your blood too thick and can lead to strokes and organ damage. She also has chronic kidney disease. She is also senile and has some dementia. She gets angry a lot and is very defiant, mostly toward me.

We live in the country, on four acres, and she likes to wander away a lot—mostly tracking her cat. Two summers ago, she disappeared from me, and I couldn't find her anywhere. I was about to call 911 when I heard a noise at the top end of the property. I found her in weeds up to her waist, in bedroom slippers, trying to pull old lumber with rusty nails in it that my brother-in-law had stacked there to burn, so now I have video cameras set up everywhere to track her.

Last summer she fell in the front yard about 100 yards from the house, looking for the cat, and she couldn't get up, so she was crawling up through the yard. She lets the cat out the front door and immediately goes to the back door and starts calling her to come in. My mother likes to get up in the middle of the night and rearrange all the cupboards in the house. Last year when the overflow on the bathroom sink rusted out and started leaking, I told her I was going to have to replace the sink, but she decided it was the drainpipes instead, so she took a hammer and fixed them. Boy did she ever.

On top of all of that, she is totally deaf, even with her hearing aids in. This makes communication with her incredibly difficult. I have tried several voice-to-text programs, but they screw up more than they work, so I have to write lots and lots of notes. I could tell you a lot more stories, but suffice it to say, she keeps me very busy.

In 2014, shortly after I took guardianship of my oldest grandson, he was diagnosed with Asperger syndrome. Asperger syndrome is a previously used diagnosis that is on the autism spectrum. He also suffers from chronic depression and obesity. In 2019 he and I started a walking program, and he lost over 60 pounds in three months. I was very proud of him.

Unfortunately, my mother's mobile home that they lived in caught fire. It was a total loss. I was able to get them a newer, manufactured home to replace it, but everything was reliant on me, and by the time I got everything up to the newer codes, and got the house set up and them back home, he had put almost all the weight back on. Since then, with my mother's further decline, it has been very difficult for me to be able to leave the house. My grandson's weight has continued to escalate, and I worry every day about his health, which is starting to decline.

I am very active with my union SEIU, United Home Care Workers of PA. In recent years we fought for and won paid training classes for homecare workers. These classes teach home care workers CPR and safety training, which I have completed. They also offer classes in working with dementia and autism patients, that I would love to take. I feel they would help me in dealing with the day-to-day tasks of taking care of my mother and grandson.

However, these are both eight-hour courses, and while they are paid training, when you have no one to cover for you, it is very difficult to get them done. As a participant-directed worker, I do not have the same collective bargaining in PA like other workers. This needs to change so we can fully advocate for ourselves. In states where homecare workers have collective bargaining, they have won important victories like healthcare and living wages, because of the workforce crisis in our industry, it is nearly impossible to get backup care, so if I get sick there is no one there to take care of them. A couple of years ago when I caught Covid, I was completely down for five days. My older sister who can sometimes help me was in Florida on vacation and there was no one to feed my mother or grandson.

This year in May, I was bit on the neck by a spider. I got very sick for almost a week, but I managed to keep working. I don't have health insurance, so I didn't go to the doctor. After a week I started to get better, and then I got sick again. I had a rash on my neck that was spreading that I had attributed to the spider bite. Then the pain started, and it got so bad I went from wondering if I was going to die to hoping that I would. I finally went to a doctor even though I couldn't afford it. I was eventually diagnosed with stage three Lyme disease, but if we had health insurance, this never would have progressed to that point.

I would like to be able to tell you, other than the fact that bugs seem to like me, that my story is a unique one, but it is not. In my time in the union, I have spoken to a lot of workers who work 90 and even 100 hours a week. I have listened to the story of a young woman from Philadelphia who after working a full day taking care of her elderly diabetic mother, she then loads her in a car, even in the dead of winter, with her blankets and medicines and drives for DoorDash all night to keep a roof over their heads. I have heard stories from workers who have contemplated suicide from depression over facing eviction from their homes.

We all know homecare workers save the system, and taxpayers, tens of thousands of dollars per year caring for folks in their homes over putting them in nursing homes or assisted living facilities, and that these folks have better overall health outcomes, but we need to come up with a plan for how to get caregivers out of poverty. Otherwise, there is no way that we can build a sustainable homecare system. We can't take care of them if we can't take care of ourselves. Thank you.

The CHAIRMAN. Linda, thank you as well for providing your own personal testimony. Look, I've used the phrase, and we you hear it a lot these days, that there's a care crisis in America or a caregiving crisis in America. You don't need to hear much more than what you just heard from our witnesses to validate that point.

We have a lot of work to do as a country. We call ourselves the greatest country in the world, and we are in terms of our military and our economy. There's no country in the world that's even close, but we're not the greatest country in the world when it comes to caregiving. We've got a lot of work to do. I want to explore some of that with our witnesses now. I'll start with Heather.

Heather, you mentioned receiving care from your parents and from paid caregivers. You also do excellent work in, in your own capacity as the outreach coordinator for the National Center on Family Support at Pitt, and we're grateful for that work. In that work. You hear from hundreds of people who need care support. You said in your testimony that paid caregiving or paid caregivers, I should say, aren't, ″necessarily to replace unpaid care, but to supplement it to allow family caregivers the time and space to care for themselves.″

I'm quoting you when I say that, but can you tell us more about having adequate caregiving services, how those services help you and those that you interact with, how they enjoy non-work activities and make it possible to have relationships outside of their family?

Ms. TOMKO. Sure. As I mentioned it and as you just repeated, I think family caregivers like my parents and paid caregivers, but with the balances right now, there's much more reliance my parents and much less reliance on paid caregivers because we have not been able to find stable paid caregivers who are able come back to really help with my care, so because of this, both of my parents definitely limit and feel stressed with their own jobs because they know that they're responsible for their work, but they're also responsible on some days for getting me out of bed so that I can go to my work, so they're declining meetings that they should be at because it's either saying no to a meeting or telling me I can't get out of bed for the day.

In terms of my own life, it's been the same. I'm declining meetings because I know that logistically it's not possible for me to attend on time because there are only so many hours in a day, and my life, my getting ready takes longer than a normal person's. You know, what might take someone who's not disabled five minutes to wash their face and brush their teeth is going to take me 10 or 15 just to get set up and get comfortable.

When I'm in my chair, I'm in my wheelchair for five hours at a time, so if I'm not comfortable and situated properly, I'm going to be uncomfortable for five hours, and that's physically dangerous and mentally and emotionally stressful.

Right now, we're all living kind of in the day-to-day and trying to just get through one day and onto the next, but if there were a better balance, if I were able to find more paid caregivers to have and take some of that load off of my parents, both mentally and physically, we would all be able to have a much less stressful life and be able to focus more on family things and less on the logistical challenges of just day-to-day life.

I see that in the many, many people I have talked to through my job. When we had a webinar and opened the Q&A, they weren't asking for paid caregivers to replace what they do. They love the people that they're caring for, but they didn't need help to be able to live their own lives and take care of themselves.

Right now, we're just not able to balance those needs appropriately, and there's a very, very heavy load on family caregivers and a heavy load, frankly, on my paid caregiver who knows that if she calls out, the burden is falling on my family.

I know that I've seen her limit her own appointments and days off and time with her own family because she does feel obligated to care for me, and I appreciate that more than I can ever say, and I wish that I knew if she called off, that I was able to find a reliable path and let her not make her career, her job into her life as well. Thank you.

The CHAIRMAN. Heather, thanks. Thanks for reminding us about your own circumstances, but also those that you hear about from those that you interact with at work. I'll turn to my left side of the table to ask a question. Maybe the same question for Delilah and for Tori, as I was calling you, Victoria, albeit a little less formal, and Linda,

Each of you shared some of the unique circumstances that you face in your caregiving responsibilities with your families, but I guess I wanted to—if you could just itemize, if you had to list, what's the most—or what's the list of the most difficult challenges you have when it comes to caring for multiple family members? Maybe Delilah, we'll start with you, and we'll go down until——

Ms. PICART. Time scheduling and coordination of time. I pay out-of-pocket for a companion for my mother and a companion for my brother. I've had instances where I've taken my mother to her doctor's appointment, and for health reasons, my brother's companion has to bring my brother back to the apartment early, so I have to maybe not stop off and get my mother lunch. I have to go to the apartment to receive my brother, and then I have to give my mother her pills, her afternoon pills, and then I could go out and get them both lunch.

There have been times when I'll take my brother out to go to the movies. That's easily a three-and-a-half-hour window. I'll have to return him and take him to back to the apartment that he shares with my mom, and unfortunately, my mom may have soiled herself, so now I have to get her to—there goes my idea of getting back and dropping him off and going shopping. Now I have to take care of her, make sure she has a shower, make sure my brother is okay because he gets agitated.

Scheduling and coordination of time for the two of them is really the biggest, and also with fragile X, my brother has a compulsion to eat, so I can't leave any food in the apartment. For instance, he saw Rocky about a month and a half ago, and he decided he could eat raw eggs, so I had to remove the raw eggs from the apartment, so there's no food in their apartment. Mom forgets to eat, so, and my brother will eat anything, so just something like that. Being conscious of portion control for the two of them because they both have diabetes, and reminding my mom that she has it because she's in a state of denial about it. Teaching my brother that he can have healthy snacks that don't include soda, things like that.

I have a saying where I have an economy of time. When I'm in the apartment, I make sure—and I'm usually there early in the morning to prepare, to give my mother her pills and prepare breakfast for her and then bring her here as a matter of fact—if it gets messed up, such as this morning she had an accident in her bed, so I had to strip the bed, help her take a shower, and then dress her, and then prepare her breakfast and stuff like that. Also, I could get here on time, and I could get her here on time, so I practice the economy of time when I'm with her and with my brother.

The CHAIRMAN. Thank you. Tori.

Ms. SNYDER. I think the hardest part is that access to childcare is difficult. Affordable childcare is difficult, but quality childcare is difficult, right? There's a lot of people I could just pass my kid to, but he's on the spectrum, so what happens if he gets overwhelmed and runs off, because he's sometimes an eloper. That stress sometimes is more. To me is not worth it. I'd rather just not do, just not go, because I could provide the better care, so that ties into what Heather had said. A lot of career—lack of advancement because I just can't be places. I can't do things. Even remote things, you still have a kid that still needs time with his mom. He's been at school all day. He doesn't want me sitting in front of a computer. He doesn't get that, right? Furthermore, I don't want to do it either. I want to play with my kid, so that's a difficulty.

There's not a lot of senior care. My mom is still fully functioning. She's wonderful, slight health concerns, but as she ages, I do not make enough money to cover childcare and potentially supporting of her. I know that she feels that worry and she feels that strain, and it's one of those things like—I guess, we'll have that conversation when we get to that point, but that's always a worry.

To navigate care services is difficult. There's not an office that you go to. If you make too much money, you don't qualify for services. If you make not enough money, you can't live because there's no way and nowhere to pay for anything, so I feel like there's this gap of everyday Americans that need a little extra, but there's no way to get a little extra, so it's not just the caregiving, but it's if I send my child to school, I need to know that he has a quality education.

We live in a more affluent district that I really can't afford because that school has a better special education department to support him. We could live in a town over, but that would not be supportive of his needs, so you struggle with that. School choice, I think, is an issue in this State as well. That's a different conversation for a different committee at a different time.

I think all these issues compile of you're just trying to make every day manageable, and you feel bad too because the caregivers we have had and the childcare we've had, they've been wonderful, amazing people, and they deserve to have the working wages as well. Neither of us should be saying, well, here's something for you today, here's extra for you. Or if they miss a day of work, they then can't take care of their family as well, and so, it feels very chicken-and-egg scenario.

I think we all just want to eat and have a fruitful farm, and so, I think conversations at a deeper level of infrastructure and care, but also having it with people that it affects their lives the most is most imperative. Having lawmakers just say, well, here's a budget and this can go is great, but I think you have to hear how that money would be allotted, and where it would go to, and how it would support the everyday person in their caregiving and childcare needs.

The CHAIRMAN. Tori, thank you. Linda?

Ms. ORNDOFF. Yes. I agree with Delilah that the hardest thing is the problems of scheduling time when you're dealing with two different, you know, participants, and especially like with my mom, she needs, you know, almost constant care.

My grandson, like I explained, he is on the autism scale, but his needs—I don't want to say his needs get overlooked—but his additional needs, like when we did the walking program before, you know, with him, you've got to make things interesting and all of that.

When we did it, you know, we would get in the car and we would drive to area parks and that type of thing. It had to be an adventure with him. You know, you can't just like take him outside and walk him around. He's not going to do it.

You know, his doctor had a long time ago described him as passive resistant and that that's how he is. He just sits down and won't do it. You know, and to try to worry about her, what she's doing and everything, and to try to take care of him.

Like I said before, you know, he discovered DoorDash a few years ago, which has been my nightmare. You know, like up until that point, I could control, you know, what food was coming into the house, so I had a little bit of control over his, you know, weight problems and things, and once he discovered DoorDash, all of that went out the window. You know, they're pulling up my driveway at 10 o'clock at night, that sort of thing.

It's just very hard to try to manage, you know, to—but I can't leave with him and take him on walking adventures and when there's no one there to cover, you know, to have with my mother there, and you know, with the shortage in the workforce in this industry, there's no way for me to be able to have somebody else there, so the scheduling thing, yes, I would say is the biggest, biggest dilemma.

The CHAIRMAN. Thank you. I want to turn to Tara. I wanted to ask a question that focuses on unpaid and family caregiving. Delilah had said in her testimony about the demands of caregiving, and I'm quoting just part of what she said in this paragraph of her testimony, but she said, "I'm tissue paper thin. I'm spent. I'm struggling." She went on from there, but you study in your work, Tara, the family. You study families and the effects of both policies and circumstances that they face, and you mentioned in your testimony, the policies often fail to center on the family experience. Can you share some of the long-term effects of unpaid caregiving on families and family members? How do you think we could better support people doing this important work?

Ms. MCGUINNESS. Certainly. The effects on caregivers, as you heard from the wisdom in the room, which really, I want to emphasize is not on average. That behind every person sitting at the table is another million people with the same problem.

The caregivers abstain from finding paid work, or following passion and education due to unpaid care duties. This is both important at the individual level for people to live their own promise, but also has a collective impact on our economy. The effects are profound, and more profound for women who do the majority of unpaid work, and who often experience in their own individual lives.

Stunted opportunity growth, especially, you can see it in the data in childbearing years. I think Tori said you went back right when kindergarten started. There is a massive increase of women in the workforce at the age in which everyone has school.

The CHAIRMAN. You said stunted. What'd you say after that?

Ms. MCGUINNESS. Opportunity.

The CHAIRMAN. Opportunity, yes.

Ms. MCGUINNESS. Opportunity, advancement. It could be career growth, it could be education, it could be fulfilling, having the freedom of fulfill your dreams, and this aggregates to a wide gender earnings gap. This is both true for the unpaid caregivers who are skipping a meeting or an opportunity because it's just not, logistically, and timing-wise, practical. You can see it in a gender earnings gap because of who caregivers are. It has massive race implications because of who paid caregivers are.

These are just a few, Senator Casey of the ways in which what we're hearing here is individual stories ladder up. Pennsylvania alone, you can actually aggregate the lost dollars to the economy, so these aren't isolated edge cases. This is a collective problem that shows up at a structural level for educational attainment as well as the larger economy. Thank you.

The CHAIRMAN. I wanted to go back to Linda for a question. Linda, you mentioned you're a member of Pennsylvania, SEIU Healthcare, a union that I know well. A union representing nurses, hospital workers, nursing home workers, homecare workers, and you've met with state officials about the needs of people who receive homecare services and the workers who provide the services.

You said in your testimony, "In recent years, we fought for and won paid training classes for homecare workers." Through the work of the union, you can now receive paid training classes on topics such as CPR and caring for patients with dementia and autism. What benefits are there to being a Pennsylvania SEIU Healthcare member for both you and for those for whom you provide care?

Ms. ORNDOFF. Well, it gives us a way to fight not only for our rights, but for the rights of our participants. For example, we currently have a bill here in the Pennsylvania house. It's House Bill 2372, which not only helps not only is looking to increase wages for participant-directed homecare workers, but also for accountability measures that the agencies and such spend a certain percentage of the money, that the funds to be able—oh boy, I really screwed that answer up. Sorry about that. It calls for accountability on the agency's part that the funds are spent toward home healthcare workers' wages and taking care of their participants.

The CHAIRMAN. Well, that I mean, that example of providing those training opportunities should be more widespread than I know it to be nationwide, so it's a good example of what we can do, and I think that's important to point it out.

Tori, you've noted that your caregiving responsibilities have affected your decisions about work. You made reference to that your last—just in the last answer you gave. We know, and this is a terrible understatement, but raising a family costs a lot, and one of the fights that I've been engaged in this battle is to point out corporate price gouging and what I call greed, deflation. I didn't make up that term, but it's a good description of what it is. Prices for food and household items being jacked up by the very companies that got these big corporate tax breaks in 2017.

Apparently, a lot of them didn't need the tax break because they were going to jack up prices after it, and it affects everything. It affects food, and housing, and gas, and you name it, and a lot of it's just pure greed, and they are very angry at me for saying that, but they better get used to it because I'm going to keep saying it.

Childcare is another cost. That's just through the roof. We've heard that today, and choosing a childcare provider has significant effects on family finances. Tori, you said at one point that you couldn't look for a job because you had no one to be with your son because of that juggling you talked about. You have exceedingly complicated mornings and well beyond the morning, I'm sure, but your workday's interrupted each afternoon so you can pick him up from school.

Can you talk more about the career decision or the employment decisions you've had to make that were impacted by the childcare needs that you have?

Ms. SNYDER. Before I had Braxton, I was an executive vice president of a multimedia company, and at a very young age, I hit all of the big goals that you should have gotten, right? I've won all the awards. I've done 40 under 40. I've gotten this, I've gotten that. I've even testified before Congress, and that's not me boasting, that's saying like I'm a capable individual, but come the pandemic, and with Braxton, he was just so little at the time, childcare was so expensive that when he first started childcare, I could afford two days a week, and so, I flexed my schedule, and I worked around, and my mother was working at that time, full-time, and so, she could sometimes pick him up, or I could pick up and drop off, but I also had childcare, but I also had a friend who was able to watch him in those gaps.

She had kids at home, too, so she was a stay-at-home mom of three, and so, I helped supplement her income and she was able to keep him if I had got stuck at work later, an event, or things like that, and so, that was really helpful in those early years, but once we hit the pandemic and the child centers were closed, and then they reopened, and then it was like, well, we're closed because of Covid, but you still had to pay even if they were closed because well, they have to pay their workers too, and people were sick, and you understand that.

One month I think Braxton went to childcare two days out of the whole month because of Covid closures, and sickness, and weather, but I still paid my $1,700 that month, but I took care of him, right? I wasn't paid, and there wasn't a way to get that money back or anything else, and so, I also made a lot of hard decisions of being able to get him into quality childcare.

I paid a lot of money for him to go to those programs. He did do a Pre-K Counts program one year, and it was really, really fantastic for him, but he was trending higher than what his classmates were, and they'd even said like, you need to get him into another program. Intellectually, he's just so advanced. If you want him to not be another statistic, if you want him to have that growth and keep it catapulting, you need to find another option for him, and so, made the really hard decision of, okay, well I'm going to enroll him in this really great preschool program, and that's when I had started my business. I was a small business coach, owned an own business, was a DEI consultant, and then also doing social media.

I was a contract worker, and at any time, I had six or seven contracts going on at one time. It's exhausting, right? Like, he would go to sleep and then you're still working, but it was the only way that I could financially afford to provide him the care that he needed.

In kindergarten, that was great, right? You're thinking, yes, we're out of childcare. I don't have to pay this amount of money every month, and then, you realize that, well, school drop off is at 8:40. Work starts at 8:30, so there's already an issue. Pickup is at 3:40, my workday goes five, so there's another issue. Even if you took the bus home, it still drops at my house at 4:15.

We're still looking at a gap of several hours of traffic and commuting, and so, afterschool programs were available and it was really great, but it was not affordable for us, and it also was a lot of tossing back and forth of him and overstimulation by the end of the day. A child on the spectrum sometimes needs routine and quiet, and he excels best with that, and so, it got to the point where I was coming home and having to undo and regulate him because he was dysregulated for so many hours, and then, also still having to work in the evenings to match my hours that got missed because I was taking him to and from work.

I'm appreciative of an employer that allows me that flexibility because I know that that's not always the case, but when it rains or it snows, and there's school cancellation, or we have off because it's prom—not quite sure why first graders need offer prom—but school board did not feel like that was viable answer when I asked.

You work from home and luckily, I have that opportunity as well, but I do economic development. I have to meet with businesses, and people, and go to meetings, and so, I'm missing a lot of the big conversations because I can't be there, but also, I'm just really tired. There's some days I don't want to people. I'm sure you've had that right after a long day of hearings.

It feels like there's a constant chase happening and it's a worry. I probably could be making more money. There's a lot of jobs that I could apply for, but that would mean that I would be bequeath to them 24 hours a day, and I'm already struggling with the gaps that I have, so I can't do that, so there's a real detriment for me for career advancement now and in at least the next 10 years.

The CHAIRMAN. Delilah, how about in your circumstance, either making a—because of caregiving responsibilities, making either a career choice or even just an employment choice?

Ms. PICART. I have an agent and the agent sends me auditions, or information from clients who are interested in booking me either for commercials, or TV spots, and stuff like that. Most recently, I had to turn down being a spokesperson for an American college, which would've given me a nice five figure drop because I did not have coverage. I would've had to travel over there. It was in Bucks County. I would've had to travel, drive over, overnight it, spend a day, and then drive back. Or another night and come back. I had to turn that down. Things like that.

Thankfully, my agent says, “Okay. Here’s the audition and here’s when it’s filming. Here’s when you would need to be available.” Unfortunately, lately, I have not been available for those times. If they say, “Hey, the week of August 5th,” I think, “No, I can’t.” My mother’s companions are away and rightfully so. They should have time to be away. My brother’s companion is having health issues, so he’s unavailable.

There was a brief period of time where my fiance’ was a way to take care of his own daughter who was recovering from a surgery, so I had to turn it down. I’ve had to turn down a number of jobs in this past year that would’ve easily given me an income of about $30,000, which is useful because I do have my own bills, and I also supplement that to my mother’s bills, and the care for her and my brother.

If Pennsylvania could provide a supplemental income to caregivers—it was so cool during the pandemic, how the President at the time wrote those checks to all of us. Right? It was helpful for me at that time. I would think caregivers, especially the ones and those receiving care at this table, to be able to look at their caregiver and say, “Wow, look, here’s $1,000 for the work that you did this week, just this week.” Isn’t it great?

We could X, Y, Z. We could get a new chair or supplement for Heather. We could provide you, Delilah, with unlimited diapers—man, I go through so many diapers for both my mother and my brother. You know, we could provide occupational therapy for Braxton, you know, so he can play, and Tori can relax. Wow, like, actually put your feet up. Isn’t that a daydream that we all have?

It’s not a handout. It would not be a handout because what I do, and what Tori, does and what Linda does, and what Heather’s people do, and what Tara does, it is work. I did not go to school for it. I did not sign up to be a caregiver. I’m not licensed, but you know what? I’m an expert in taking care of my brother and my mother.

I could probably help out with Tori because I understand what it’s like to have a boy with autism, and Linda, I could probably do something with your grandson, because I’m familiar with that community, but I can’t call myself an expert to them. I could only call myself an expert to Eric and Vivian.

The CHAIRMAN. Thank you for reminding us about the impact on the decisions a caregiver has to make about——

Ms. PICART. Excuse me, Senator, may——

The CHAIRMAN. Yes, sure.

Ms. PICART [continuing]. I add one more thing? It is so important that the language includes siblings. There are a number of sibling advocates who are now sibling advocates and caregivers, and if you look at the language, it says “mother, father, relative caregiver.” I’ve seen this at Rite Aid. I’ve seen this at Best Buddies, and I’ve been the longest relationship that my brother has in his entire life, and I will continue to be until either I pass or he passes. Yet, there is no literature anywhere that verbalizes and acknowledges the work that a sibling does as a caregiver. I just needed to add that.

The CHAIRMAN. Good point. Tara, I wanted to ask you a question about the financial needs of American families in terms of these caregiving costs that we've heard we've heard, I should say several people have made a reference to.

We know that childcare is a huge expense for families sometimes taking up. We've seen all kinds of data on this. Twenty percent, I guess, in some states, higher among low-income families. We also know that caregiving for an aging parent can result in a significant loss of family income, especially for women, as you and others have pointed out. That the loss of work has an impact, as we just heard.

I spoke to, not too long ago, a woman from Scranton who left her job that paid $80,000 a year, and took a more flexible job at a hardware store that paid $28,000 so that she could care for her mother. From your perspective, what are the most important policies we should have in place to support families who must care for their loved one and ensure that they're not forced into poverty?

Ms. McGuinness. There's no such thing as unpaid care, so people provide it.

The Chairman. Yes.

Ms. McGuinness. Just to kind of go through the list of policies, we've heard a bunch of them around the table. Compensate caregivers, unpaid caregivers. There are mechanisms, and we know the U.S. Senate can do this because it's been done at least once, and you have a bill to take this further, but in 2021, Congress passed the American Rescue Plan and raised the wages of millions of homecare workers in all 50 states in a temporary way around Covid. Was it enough? Absolutely not, but was it done, and so, it could be done more? Absolutely. Similarly, in the same, you know, rescue plan, the child tax credit was expanded vastly. This cut poverty in half in a single year.

The evidence is fantastic. I know you know this. We stopped doing it. It made a profound difference. A lot of that covered the gap for childcare, you know, caregiver tax credits as well, and you know, there is both a financial investment across the board, childcare, paid family medical leave that's up here in Pennsylvania that we came very close at the federal level. We could come back to that.

I want to say a word, though. It is both about making financial investments in early, middle of life, and long-term care at a federal level. It also means we have to make these things work. I think you heard, you know, the ability to have medical records from 30 years ago transfer. You know, the simple things like an application process.

Many, many people miss out on their tax credits, their earned income tax credits. Twenty percent of people leave it on the table because if you don't make enough money to pay taxes, you don't have to pay taxes. Why would you have to pay taxes in order to get your tax credit? And that is measurable. Cash for households that has a two-generation impact.

This is a kind of set laundry list. Early education, long-term care, paid family medical leave, and being in a feedback loop where these policies really work. Where the call times, the applications, aren't impossible to read, so it's both investing the funds and making them usable.

The Chairman. Thank you. Heather, I wanted to move to a question for you. You discussed reliance on paid caregivers as well as the care provided by your family. As you noted in your testimony, your parents are aging, and at some point in time, they'll no longer be able to provide some of your basic needs.

You say in your testimony, "worry every single day about my future, what my future could look like." And you're concerned that you might have to move to an assisted living facility or other type of more institutional setting. What do you need to ensure that you don't lose, and as you say, lose what you made reference to, which is, and I'm quoting, "a full and vibrant life."

Ms. TOMKO. I think I might sound like a bit of a broken record here, but the most important thing for me to keep my life and for me to continue to live as full a life as I have now is ensuring that paid caregivers are available and they are compensated well enough that they can consider it a career.

You know, as I mentioned, my care is not challenging, necessarily, but it is detailed. The small details matter into just making me comfortable going through about my day, and so, if I have to teach the details of my care to a new caregiver every day or every week because of that 60-plus percent turnover that you mentioned, I would be physically in danger of being injured from someone who doesn't understand my personal care needs, and emotionally and mentally worn down from having to go through the same thing day, after day, after day, trying to help someone understand.

If caregivers were more stable, if they were paid to consider this a stable career, I would be able to have a rotating schedule of maybe five caregivers who are able to grow with me, learn with me, understand my care, and have that relationship that works for both of us, because right now, like so many of you already mentioned, the real experts of my care right now are my parents, and that is not feasible long-term, nor should it be. You know, I am 35. I would love to be able to live on my own in the community. I lived in the dorms at college, and loved it and thrived, but I can't live on my own right now knowing that I might have to call my parents at 11:00 p.m., and saying, "Hey, I'm so sorry. A caregiver called off, and we tried everyone we could, and no one is available."

My life is vibrant now, but could be even fuller, but it feels like I can't wish bigger than what I have right now because it feels like such an impossible ask, and making myself smaller to be content with what I have now, and I love my parents, and I'm so grateful for the care that they do offer me, but I shouldn't have to be relying on them, and without compensating caregivers for the value of the work that they do, that will never be possible for me. Thank you.

The CHAIRMAN. Well, and your independence is important to you like it is for everybody else, right? I know we're getting close on time. I wanted to ask one more question to the whole panel. This'll be what you might call the lightning round, in the sense that, I hope, if you can, if you'd be willing, and some of the other answers each of you gave, made reference to kind of an action item list.

I think as a conclusion so that we can be reminded of what our, my responsibility is, as well as any elected official at any level of government—I'm not going to call out other levels of government. I'm a federal official, so I'll put the burden on the federal government for today, but we all play a role in no matter what level of government, but if you could just outline what you hope the U.S.

Congress, the House and the Senate, and the next administration would do to provide the kind of policy agenda that would address some of the most urgent needs, and maybe we'll start with Linda over here.

Ms. ORNDOFF. Well, I'd like them to just help us get the resources we need to make homecare a viable occupation. I mean, it is currently is with the low wages, no benefits, you know, no retirement, or anything. People can't afford to do this type of work, you know, when they can go to, say, a Target or Sheetz, and make more money.

The CHAIRMAN. Yes.

Ms. ORNDOFF. Then they can be in a home healthcare worker if we had the proper resources and we could make this a viable occupation. That we would have backup when we need it like when I got sick with the Covid or sick with, you know, Lyme disease. I wouldn't have to worry that there's no one there to take care of them, to feed them, or cleanup, or anything like that, or get them to appointments and things. Basically, that's it. I mean, we need resources to make it a legitimate occupation.

The CHAIRMAN. Linda, thank you. Tori?

Ms. SNYDER. I think it's important for policymakers and lawmakers to understand that they need to put their differences aside. This isn't a Democrat thing. This isn't Republican thing. This is about humanity and people, and I'm tired of name crawling at a level of—just it seems that like our children on the playground know rules better than the many policymakers do.

I think, putting ego aside and thinking; what do we need to do to be able to provide quality of life and quality of care for Americans? I think that you are seeing the detriments of health, the social detriments that are happening to us, this weight that is hitting us of just all of the worries that we face leads to healthcare issues, which is a burden onto our system, but also, the mental health issues, which is another burden to society, and to the people, and to our systems.

I think the paid leave for all, the child tax credits, the elder care, the care ability and services, and access to affordable healthcare. These basic rights is why we elect our officials, and I think that they need to remember that that's what they're doing at the end of the day for us.

The CHAIRMAN. Tori, thank you. Delilah?

Ms. PICART. Recognition to caregivers, just like you would recognize police, firemen, and EMS. Letting them have some sort of license so we have that recognition. Providing free mental health care to caregivers. I'm fortunate, like I said, I do have a therapist, but sometimes talking to her twice a month is not enough for me, and definitely wages. Living wages, or for some of us, supplemental income so I can comfortably not have to, you know, take from Peter to pay Paul. I can pay my bills and take care of my family. Thank you.

The CHAIRMAN. Thank you. Everybody's doing their—making their lists very quickly, and I know, Tara, you had provided a list earlier. Anything you want to add to what you said earlier or anything you want amplify?

Ms. MCGUINNESS. To your colleagues, listen to families and keep them in the loop as you design policies as you're doing today. That means building solutions are not about one policy. The same family is doing elder care and early care, and this will take investment, real dollars that we need to spend across the life spectrum, and the wages. We will not get quality care until we have quality wages, and $13.42 cents is not acceptable.

The CHAIRMAN. Yes. I mentioned—make one quick commercial here for the question of revenues. You know, we often hear in Washington, oh, well these are great things to talk about, but there's no revenue, right? There's just no way to do it.

A big part of the reason why there hasn't been the revenue is because we've made choices now for 40 years. When I say we, I mean the Congress, over the last 40 years to have a tax code which is rigged for the top, and that's where the revenue is, right? When you do that decade after decade, it constrains the revenue.

The good news here is we got a big opportunity in 2025. No matter what the outcome of this year's election, there is going to be a big tax moment. The biggest tax bill in probably 25 years, if not longer, and that is the moment where we're going to make some fundamental choices about whether or not we're going to commit revenue for caregivers, for families, for those who need a break and need help, or whether we're just going to do the same old thing, which is the very—we get much, much wealthier, and big companies get these huge, and I would argue obscene, and I use that word purposefully, obscene tax breaks.

There's not a big mystery here. There is revenue. If you align the needs that families have with the values that should emanate from that with your tax choices, so really going to make the right choices in 2025 or not, and if we make the wrong choices, it's not going to be another chance in 2026 or 1927, and go forward a lot of years. Got to win that tax fight in 2025. It is a big, big moment for all these issues we talk about, and I hope people bear that in mind when they're making a voting decision.

Finally, Heather, we'll end with whatever you'd want to say about policy.

Ms. TOMKO. Sure. I think coming along with what you just said, what I would really like people to remember is that my life as a disabled person has value. The lives of the people who care for me, those lives have value, and it's really important that we do put money behind policies that add to the value of those lives, and policies that see those lives as having value, and for us is just to live lives that other people already take for granted and without paying money, find policies that support the direct care of workers, and policies that support increased wages for caregivers, there's no way for me to believe that people see the value in my life. Thank you.

The CHAIRMAN. Heather, thanks so much.

I want to thank Heather. I want to thank Tara, Delilah, and Tori, and Linda for their testimony and the answers to questions that they gave, but most especially, for sharing their own experiences, the struggles of their own lives, and that of their families, and of people that they interact with.

We've heard about so many challenges faced by caregivers and those who need care. Each of our witnesses who told a story about their own caregiving lives and their own stories have overcome so much in their lives in ways that I can't even imagine. I've never had to overcome the challenges that I've heard articulated today.

To use a line that my father used many, many years ago, so many stories that we've heard here today and the struggles in their lives, the stresses in their lives, the challenges they face each and every day, not intermittently, but each and every day, could be could be encapsulated by saying that they have led, "quietly, triumphant lives."

They've already had to overcome so much, and to triumph over those challenges, and stresses, and horrific circumstances. We're just grateful that they're willing to share. I think in a word, it's a chronicle of sacrifices that they've made sacrifices to care for their loved ones, including leaving their jobs to become full-time caregivers, starting their own businesses so they have adequate flexibility to accommodate their caregiving schedules, and moving family members closer in order to provide day-to-day care.

These efforts often go without recognition. They are in a word, unheralded, and many caregivers are "on the clock" all the time. Whether it's to help with finding high quality and affordable childcare, or caring for an aging family member or a relative with a disability, or sometimes all of the above. All at once. As Linda said, perfectly, "We can't take care of them if we can't take care of ourselves."

So, we're going to continue the efforts that I've undertaken and others have undertaken to increase funding for programs like Medicaid, home and community-based services, to ensure that no one has to wait for the care that they need.

I'm also working to permanently expand both the child tax credit and the child and dependent care tax credit, two separate tax credits. One that's more broader in its impact because it's a tax credit for families raising children, and that family decides what they spend it for, mostly, in most instances, food, but food, or rent, or childcare.

Then, there's a separate and distinct tax credit, the child and dependent care credit. That's a tax credit just for caregiving or for childcare. We know that caregiving touches all of us, and the federal government, as I've said now, multiple times, must do more. Must do more to support those who need care and those who are our caregivers.

And when I say must do more, it starts with the tax code. It starts with appropriations. It starts with making these issues a priority, not an afterthought, not with what extra money's left over when you gave all away the store to the top, but making it a priority when the tax debate starts, and making sure we win those tax and revenue battles. I want to thank all of our witnesses, again, for contributing their time and sharing their experiences.

The hearing record will remain open for seven days or until next Wednesday, August the 14th. Thanks everyone for participating. This hearing is adjourned.

[Whereupon, at 11:36 a.m., the hearing was adjourned.]

APPENDIX

Prepared Witness Statements

U.S. SENATE SPECIAL COMMITTEE ON AGING

"FROM INFANCY TO AGING: THE EFFECTS OF CAREGIVING ACROSS THE LIFESPAN"

AUGUST 7, 2024

PREPARED WITNESS TESTIMONY

Heather Tomko

Good morning, Chairman Casey. Thank you so much for allowing me to share my testimony today. My name is Heather Tomko - I'm a 35-year-old woman and a lifelong Pittsburgher, a graduate of both Carnegie Mellon University and the University of Pittsburgh, and a current employee of Pitt as well. I'm also disabled - I have a progressive, genetic neuromuscular disease called Spinal Muscular Atrophy (SMA). I've never been able to walk, and I've used a wheelchair since I was about two years old.

Growing up with a disability like SMA means that my life looks a bit different than most people's. I need help doing most of the things people tend to take for granted - getting in and out of bed, using the bathroom, taking a shower, getting dressed, and even brushing my hair. That help has come in various forms over the years. Up until college, my parents were my sole caregivers, and I relied completely on them. When I was accepted to Carnegie Mellon and decided to live in the dorms on campus, my family and I had to figure out how I would get the help I need while living away from home, and that was my first experience with paid personal care attendants (PCAs). Since graduating from college, I've moved back home with my parents and my sister, who shares my disability, and have a mix of unpaid care from my parents and paid care through PCAs.

I learned quickly while at college how much of an adjustment relying on PCAs was going to be for me. Not only in terms of having to explain and be comfortable with strangers doing my care (though that was also new to me), but in terms of the management of my PCAs schedules. I got my PCAs through an agency, who coordinated the hiring and scheduling of my PCAs to fill the hours I'd been allotted through my Medicaid waiver.

I realized that while the agency was in charge of my schedule, I was ultimately responsible. If a PCA called off for one of my shifts, which happened not infrequently, I was the one without care if the agency couldn't find a replacement in time. I was the one making frantic phone calls to the agency every few hours checking in with them, and I was the one who had to call my parents and ask my mom to spend the night with me in the dorm when the agency wasn't able to find anyone in time. All while also trying to adjust to college life, make new friends, finish my homework assignments on time, and study for exams. Nothing adds to your stress level quite like knowing you have a midterm the next day, and not being sure if you will have a way to get out of bed beforehand to actually go take the exam.

This lack of stability with PCAs during my time at Carnegie Mellon was a large part of my decision to move back home after college. At least at home, I would have my parents as backups already in the same place, and I wouldn't need to make any 11:00 p.m. phone calls after another last-minute call off. Over the years, I have cobbled together a patchwork of care, luckily finding a handful of consistent PCAs (though never enough to actually fill all the hours allotted to me) with my parents filling in the rest of the gaps.

Finding consistent care is an important distinction, and a detail that is often overlooked. My care, while not overly difficult, does require explanation, and training, and a little bit of getting used to. When someone is putting me into my wheelchair where I'll spend the next five hours in the same position, it's important that I'm comfortable and supported correctly while I'm there, and if I have a revolving door of PCAs, rather than a handful of consistent people, it becomes near impossible for me to have my needs actually met properly, because by the time a PCA and I have settled into a comfortable routine, they're already moving on.

While I have a patchwork system that is manageable for now, I worry every single day about what my future could look like. I'm 35 right now, and my parents are in their 60s. I'm incredibly grateful that they're still able to lift me, and to help me with the more physical aspects of my care, but I know that this won't be the case forever - they're aging, and at some point in the not-so-distant future, they're not going to be able to care for me (and my sister) like they do now, and I'm terrified what that will mean for me. If I can't find consistent care, my only option would be to move into an assisted living facility, and leave my full and vibrant life behind.

While these are only my own personal experiences, I also see them mirrored every day in my professional life. I'm the Outreach Coordinator at the University of Pittsburgh's National Rehabilitation Research and Training Center on Family Support. In this role, I serve as the liaison between academia and the larger family caregiving community. In my interactions with both caregivers and people receiving care, I found that the most common comments and questions I got were about how they, as family caregivers, were shouldering the majority of care for their loved ones, and how they were struggling to find and keep PCAs. While we often look at ″paid caregivers″ and ″unpaid caregivers″ as two different silos, both actually exist intersectionally along the care continuum. Many family caregivers are looking for PCAs for their loved ones as well - not necessarily to replace their unpaid care, but to supplement it - to allow family caregivers the time and space to care for themselves, as well.

While this has been a challenge for years, I've found that it's gotten exponentially worse following the pandemic - it's gotten to a crisis level that I've never experienced before, and I know that the problem is multifaceted, but it's clear that one major issue is the stagnant wages for PCAs. I've mentioned how pivotal getting this care is to me and my life - without it, I could quite literally be stuck in bed all day - but the wages PCAs receive do not reflect how critical their services are. Someone can actually make more and have a higher chance of growth and promotion by working at Target than they can by working as a PCA. We've seen companies raising their wages to entice people back into the workforce following the pandemic, but I haven't seen that happening for PCAs. So, I'm seeing what has been a long-standing issue now brewing into a perfect storm of losses in the workforce with stagnant, non-competitive wages, with no changes in sight.

Increasing wages to a competitive level for PCAs is long overdue. I urge you to act on this before it's too late for me and the thousands of others who rely on care to live our daily lives. Thank you so much for allowing me the chance to speak with you today, and to share my experiences and submit my testimony.

U.S. SENATE SPECIAL COMMITTEE ON AGING
″FROM INFANCY TO AGING: THE EFFECTS OF CAREGIVING ACROSS THE LIFESPAN″
AUGUST 7, 2024
PREPARED WITNESS TESTIMONY
Tara Dawson McGuinness

″The [youngest grandson] is autistic, you know what I'm saying. I can't take him everywhere ‘cause I have to hold his hand 24/7. Even walking down the street, I can't release his hand because he will wander off.″

These are the words of Walter, a grandfather and sole caretaker of two children in Philadelphia, whose perspective I am honored to lift up at this hearing.

My name is Tara McGuinness. I am the Executive Director of the New Practice Lab, a team based at New America, focused on delivering better policy and public services for families with young children. I am grateful to join you to talk about the importance of focusing on the care needs of families.

My testimony today relies on both data gathered by our team and the experience and expertise of people like Walter - families who are part of our Thriving Families Project[1], an ongoing effort in multiple states, including Pennsylvania, to listen to families and build a holistic picture of what enables them, in their own words, to thrive.

At the New Practice Lab, we help policy makers build new policies in a closer feedback loop with families - exactly what we are doing today. We are so glad to be a part of this important field hearing.

Unfortunately, at a policy level, too often we don't center on the family experience. We often approach phases of life as separate challenges: early childhood education and care, paid family and medical leave, families members that are aging or have a disability.

However, care needs - for children, for parents, a sibling with a disability - often show up all at once for a family. If we are raising young children, we might also be caregiving for our parents. If we are grandparents, we might be unexpectedly raising our grandchildren.

In Pennsylvania, more than 76,000 grandparents live with grandchildren for whom they are responsible, and 47% of those grandparents are in the labor force.[2] At the other end of the age spectrum, millions of youth and young adults provide care for family members.[3] Other families with loved ones with disabilities have different care needs.

I know this to be true. Like 47% of Americans in their 40-50s, I have young kids and aging parents.[4] Like more than 20 million American families, mine cares for someone with disabilities.[5]

Families cycle in and out of needing care. One in six non-caregivers expects to become a caregiver within two years.[6]

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[1] New Practice Lab, New America, ″Co-Designing a Thriving Family Life″, https://www.newamerica.org/new-practice-lab/blog/co-designing-a-thriving-family-life/ ″To date, we have conducted 4 co-design workshops with 35 people from families with a wide variety of backgrounds and experiences, including families from a variety of racial and ethnic backgrounds, those that live in rural, urban, and suburban communities, and have lived experience with a broad swath of social welfare programs across the, and local levels.″

[2] U.S. Census Bureau. ″Selected Social Characteristics in the United States.″ American Community Survey, ACS five-Year Estimates Data Profiles, Table DP02, 2022, https://data.census.gov/table/ACSDP5Y2022.DP02?g=040XX00US42

[3] Armstrong-Carter et al. ″The United States should recognize and support caregiving youth″, Social Policy Report, https://srcd.onlinelibrary.wiley.com/doi/10.1002/sop2.14. Accessed July 31, 2024

[4] Kim Parker and Eileen Patten, ″The Sandwich Generation Rising Financial Burdens for Middle-Aged Americans″, Pew Research Center, www.pewresearch.org/social-trends/2013/01/30/the-sandwich-generation/. Accessed August 1, 2024.

[5] In 2019, out of 79.6 million family households in the United States, 25.7% of them had at least one family member with disability. 25.7% of 79.6 million is around 20 million family households. Natalie A. E. Young and Katrina Crankshaw, U.S. Census Bureau, Social, Economic, and Housing Statistics Division Demographic Directorate, ″The Demographics of Disability in the Family: Prevalence, Characteristics, and Implications for Financial Well-Being″, https://www.census.gov/library/working-papers/2023/demo/SEHSD-WP2023-22.html. Accessed August 1, 2024

[6] U.S. Center for Disease and Prevention, ″Caregiving″, https://www.cdc.gov/aging/data/infographic/2018/aggregated-caregiving.html. Accessed August 1, 2024

It is too hard to raise a family and find care for loved ones

Today, in the United States we make it way too hard[7] to start and raise a family. Household costs go up precipitously with the birth or adoption of a child, right at the same time that wages typically go down.

Every year, about 130,000 babies are born in Pennsylvania. More than 2,000 children are adopted.[8]

Pennsylvania, like most states, has no state paid family and medical leave program. When a new baby is born, parents are on their own to figure out how to manage infant care and earn a living.

Nationally, just 27% of workers have paid family leave through their jobs to care for a new child or a seriously ill loved one, and only 40% have personal medical leave through an employers' short-term disability insurance policy, including for pregnancy-related health and recovery issues.[9] Access varies dramatically by industry, occupation, and wage level, among other factors, leading to dramatic disparities that place the greatest burdens and risks on workers and families with fewer resources.[10] The majority (61%) of private sector workers (making less than $14/hour) do not have paid sick time for short-term illness related absences.

Having a child is just the beginning. Being able to make a living and raise kids gets even more challenging as school in most communities doesn't start until kids are five and parents need childcare to work. In Pennsylvania, there are nearly 796,000 working parents with children ages birth to five.[11] The majority of them need childcare.

That care comes at a steep cost. In 2023, the average Pennsylvania family paid about $14,000 for one year of center-based child care - per child.[12] That's 11.5% percent of the median family income. There is wide geographic variation, with the annual cost of center-based care ranging from around $8,000 in some counties to upwards of $18,000 in others.[13]

–In Philadelphia and Cumberland counties it is on average $14,078 for just one year of care.

–In Dauphin County, Allegheny County, Mercer County and Washington counties it is closer to $13,772.

Affordability is only one piece of the equation though. Child care staffing shortages mean there simply are not enough providers to meet the needs of families seeking care. In a recent survey, Pennsylvania providers responded that being fully staffed would allow them to care for about 16,500 more children.[14]

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[7] Robertson et al., ″Raising Young Kids in America Has Become Hell, and the Government Should Finally Acknowledge That', New Republic, newrepublic.com/article/167369/young-children-parents-seniors-government-programs. Accessed August 1, 2024

[8] U.S. Department of Health and Human Services, Administration for Children and Families,Administration on Children, Youth and Families, Children's Bureau. ″The AFCARS Report: Pennsylvania″ Estimates as of May 9, 2023. Accessed on July 31, 2024https://www.acf.hhs.gov/sites/default/files/documents/cb/afcars-tar-pa-2022.pdf
and March of Dimes PERISTATS, ″Births″, Data for Pennsylvania,https://www.marchofdimes.org/peristats/data?reg=42&top=2&stop=10&lev=1&slev=4&obj=3&sreg=42. AccessedAugust 1, 2024.

[9] 9Vicki Shabo, ″A Nation of Paid Family Leave Have- and Have-Nots Characterizes the United States in 2023″, New America, https://www.newamerica.org/better-life-lab/blog/bls-family-leave-2023/ Accessed August 1, 2024

[10] 10Vicki Shabo and Hannah Friedman, ″Health, Work, and Care in Rural America″, New America, https://www.newamerica.org/better-life-lab/reports/health-work-and-care-rural-america/ . Accessed August 1, 2024

[11] Sandra Bishop and Steve Doster, ″$6.65 Billion: The Growing, Annual Cost of Pennsylvania's Child Care Crisis″, Council for a Strong America,https://strongnation.s3.amazonaws.com/documents/1608/2735f9c4-fa3c-4e39-8516-ed2de992b084.pdf?1677601740&inline;%20filename=%22$6.65%20Billion:%20The%20Growing,%20Annual%20Cost%20of%20Pennsylvania%E2%80%99s%20Child%20Care%20Crisis.pdf%22. Accessed August 1, 2024

[12] Child Care Awarer of America, ″Childcare Affordability in Pennsylvania″,https://info.childcareaware.org/hubfs/2023%20Price%20Fact%20Sheet/Pennsylvania%202023—Price%20of%20Care.pdf. Accessed August 1, 2024

[13] U.S. Department of Labor, ″Childcare Prices as a Share of Median Family Income by Age of Children and Care Setting″, National Database of Childcare Prices,https://www.dol.gov/agencies/wb/topics/childcare/median-family-income-by-age-care-setting. The New Practice Lab team has organized this information into an accessible spreadsheet here:https://docs.google.com/spreadsheets/d/1iAsaBrWeLJ3X8mW—t2—otJozvdoy3kC9/edit?usp=sharing&ouid=113629679965876143693&rtpof=true&sd=true

[14] Start Strong PA, ″Pennsylvania's Child Care Crisis September 2023 Survey Results″, https://static1.squarespace.com/static/5c2e545d0dbda3cf1389658c/t/661ff30ee875e904e6a8a384/1713369870722/SSPA-Pennsylvania-Fact-Sheet.pdf. Accessed August 1, 2024

The cost of living for families with young children is especially difficult, but meeting the care needs of a family isn't only a challenge for families with young kids. Whether because of a long term disability or a short-term medical need (like recovering from cancer treatment), families need flexibility, access to care, and support when they are providing care to loved ones. 14% of people in Pennsylvania have a cognitive, hearing, vision, or ambulatory disability, or one that makes self-care or independent living difficult.[15]

Parents and primary caregivers are in a tight spot trying to put together a puzzle that balances affordability, accessibility, and quality - all while earning a living.

Caring for each other as we age

Modern science has enabled us to live longer than at any point in history - shifting our need for care dramatically.

Currently, Pennsylvania is home to 3.4 million older adults, the fifth highest total in the country.[16] By 2030, one in four Pennsylvanians will be 65 or older. Most of these seniors prefer to remain in their homes and communities instead of living in an institution.[17]

To meet this demand, Pennsylvania will need to recruit 275,000 new home care workers in the next six years, but poverty wages for caregivers and challenging working conditions mean that today these roles have an annual rate of turnover of 64%.[18]

Work, the carers and the caring workforce

Here in Pittsburgh, child care workers make an average of $13.42 per hour, which is about $28,000 per year.[19] If they support a child, they would need to come up with almost $40,000 more to have a modest living standard.[20] Demand for child care workers exceeds the size of the existing workforce. The industry continues to struggle from the impacts of the pandemic. Jobs are available, but hiring and retaining folks is a particular challenge in the child care industry.[21] A key driver of this scarcity - wages are far too low, and because this work force is largely women and largely women of color these wage inequities have rippling effects on our communities.

There are and there will need to be millions of care jobs, especially home care jobs, that pay living wages. Today there are 3.7 million home care workers, according to BLS data.[22] In fact, home health and personal care aide is the most common job in the United States.[23] Still, the need for home care outpaces the availability of people to provide that care. Employment of home health and personal care aides is projected to grow 22 percent from 2022 to 2032, much faster than the average for all occupations. About 684,600 openings for home health and personal care aides are projected each year, on average, over the decade.

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[15] United for ALICE (Asset Limited, Income Constrained, Employed), ″Financial hardship for people with disabilities: Pennsylvania″, https://www.uwp.org/wp-content/uploads/ALICE-in-Focus-Disabilities-Pennsylvania.pdf. Accessed August 1, 2024

[16] Pennsylvania Department of Aging, ″Aging Our Way, PA: A Plan for Lifelong Independence″, https://www.aging.pa.gov/publications/MasterPlan/Pages/default.aspx. Accessed August 1, 2024

[17] United Home Care Workers. ″Where does the money go? Funding Accountability for Pennsylvania's For-Profit and Private Equity-Owned Home Care Agencies″ https://uhwp.org/wp-content/uploads/2023/04/REPORT%E2%80%94Where-Does-the-Money-Go-2023.04.05.pdf. Accessed August 1, 2024

[18] ibid

[19] U.S. Bureau of Labor Statistics, Occupational Employment and Wage Statistics for Pittsburgh, PA, May 2023. $13.42 per hour x 40 hours per week X 52 weeks = $27,913.6 annual wage. https://www.bls.gov/oes/2023/may/oes—38300.htm#39-0000. Accessed August 1, 2024

[20] Economic Policy Institute's Family Budget Calculator, January 2024. Data are in 2023 dollars, https://www.epi.org/resources/budget/. Accessed August 1, 2024. For an adult to support a child with a modest living standard, a worker in the Pittsburgh metro area needs $67,418 annually. The gap is $67,418 - $27,913.6 = $39,504.4

[21] The Center for American Progress, ″The Child Care Sector Is Still Struggling To Hire Workers″, https://www.americanprogress.org/article/the-child-care-sector-is-still-struggling-to-hire-workers/. Accessed August 1, 2024

[22] U.S. Bureau of Labor Statistics, ″Occupational Outlook Handbook: Home Health and Personal Care Aides″, https://www.bls.gov/ooh/healthcare/home-health-aides-and-personal-care-aides.htm#::text=in%20May%202023.
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Policy hasn’t kept up to meet the needs of our lives

In just a few generations we moved from a typical family having one person at home caring for the children to most American kids being raised by two working parents, and more and more often those working parents are also providing some level of care for their own aging parents.

Every year, unpaid family caregivers provide about 80% of care services to their communities - a $600 billion US dollars worth of contribution.[24] Women are more than two times more likely to be giving this unpaid care. Inadequate child care options cost Pennsylvania $6.65 billion in lost earnings, productivity, and revenue.[25] This is a structural economic issue, not just a personal one.

We have experienced dramatic shifts in how we live, and while we’ve made important advancements in our physical infrastructure to keep pace with our economy, we have not done the same for the care infrastructure that equally supports our families and our workers.

This isn’t an impossible dream, we know what works

Nearly all countries around the world, and even 13 states across America, have paid leave policies that support families. We have significant evidence demonstrating the positive impact these policies have across economic, health, and social outcomes.[26] Making caregiving a legislative priority need not be partisan - 82% of voters support making it easier for people to care for their loved ones.[27]

Thich Nhat Hahn said, ″Caring is the bridge that connects us to one another.″ Today, we are in deep need of more connection and policies that enable us to care more deeply for each other. This hearing is a step on the path for federal policies to anchor into the voices of what families are asking for: policies that support them through all the moments of their lives that require care.

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Attachment: Care Learnings from New Practice Lab Thriving Families Project (PA)

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[24] Reinhard et al., ″Valuing the Invaluable 2023 Update: Strengthening Supports for Family Caregivers″, AARP, https://www.aarp.org/pri/topics/ltss/family-caregiving/valuing-the-invaluable-2015-update/. Accessed August 1, 2024

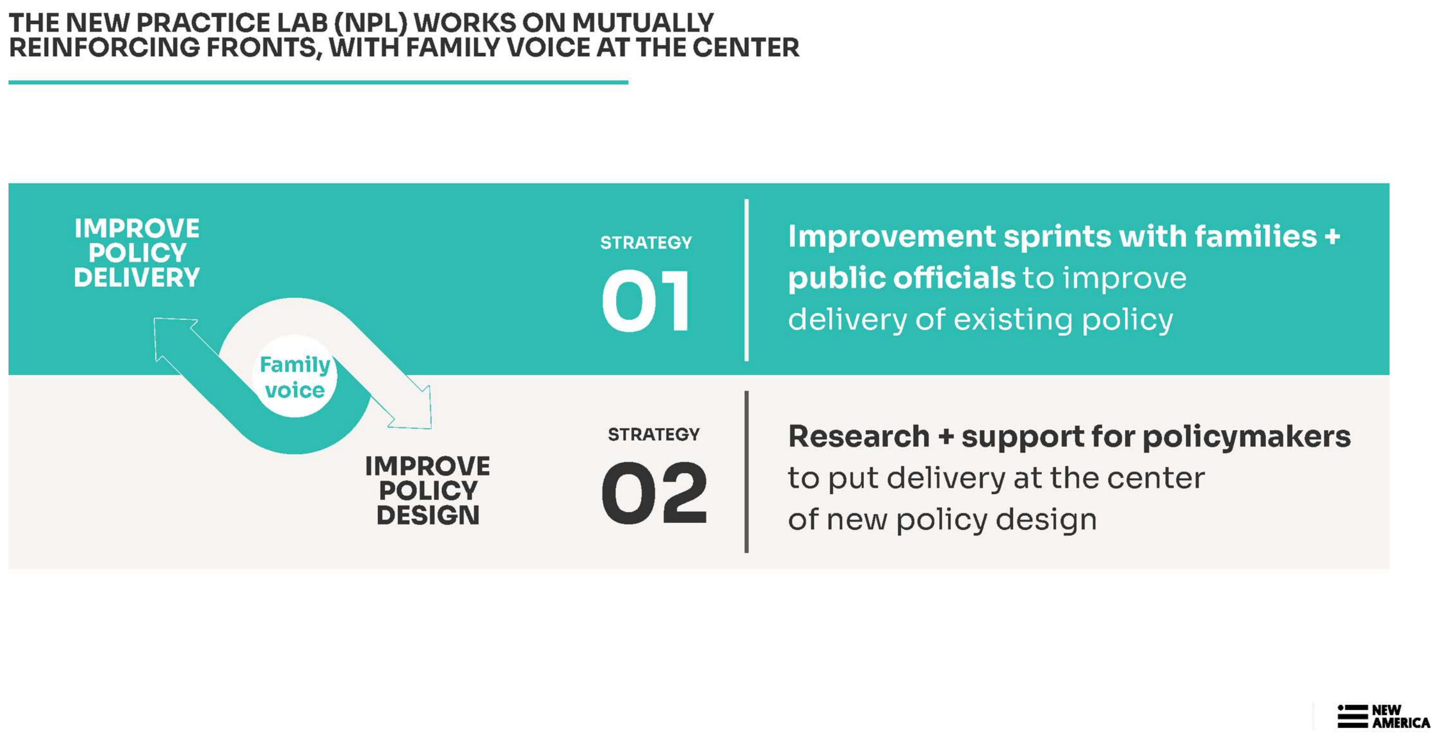
[25] Sandra Bishop, and Steve Doster, ″$6.65 Billion: The Growing, Annual Cost of Pennsylvania’s Child Care Crisis″, Council for a Strong America, https://strongnation.s3.amazonaws.com/documents/1608/2735f9c4-fa3c-4e39-8516-d2de992b084.pdf?1677601740&inline;%20filename=%22$6.65%20Billion:%20The%20Growing,%20Annual%20Cost%20of%20Pennsylvania%E2%80%99s%20Child%20Care%20Crisis.pdf%22. Accessed August 1, 2024

[26] Vicki Shabo, ″Rural Pennsylvanians Must Travel Long Distances to Hospital-Based Health Care″, New America,https://www.newamerica.org/better-life-lab/blog/rural-pennsylvanians-must-travel-long-distances-to-hospital-based-health-care/; Kathleen Romig and Kathleen Bryant, ″A National Paid Leave Program Would Help Workers,Families″, Center on Budget and Policy Priorities,https://www.cbpp.org/research/economy/a-national-paid-leave-program-would-help-workers-families; Addati et al., ″Care at work: Investing in care leave and services for a more gender equal world of work″, International LabourOrganization,https://www.ilo.org/publications/care-work-investing-care-leave-and-services-more-gender-equal-world-work. Accessed August 1, 2024 Washington Center for Equitable Growth. ″What does research say about care infrastructure?″https://equitablegrowth.org/wp-content/uploads/2021/04/041521-care-infrastructure-fs.pdf. Accessed August 1,2024

[27] Morning Consult on behalf of Pivotal Ventures and BPC Action, ″Voter Sentiment on Caregiving in the U.S.″, https://bpcaction.org/wp-content/uploads/2024-Caregiving-Poll-Results.pdf. Accessed August 1, 2024

NEW PRACTICE LAB

Care Learnings from Thriving Families Project



THE NEW PRACTICE LAB (NPL) WORKS ON MUTUALLY REINFORCING FRONTS, WITH FAMILY VOICE AT THE CENTER

STRATEGY **01**

Improvement sprints with families + public officials to improve delivery of existing policy

STRATEGY **02**

Research + support for policymakers to put delivery at the center of new policy design

Thriving Families

Thriving Families is NPLs multi-year, participatory research effort engaging low income families with young children directly to **deepen our understanding** of the challenges of raising a happy and healthy family, and how families would want their communities and support systems to work to encourage a thriving life.

We also seek to understand how those challenges, and goals, **may evolve as their family evolves**.

Structure of this project

We are engaging different states across the country, and may be in different phases with each community at the same time.

PHASE ONE

Co-create a vision

- Participatory research workshops w/ small groups of families

PHASE TWO

Evolving, ongoing discussion

- Iterative, qualitative listening over time

PHASE THREE

Contextual data

- Informing themes heard from families with quantitative data

Continuous synthesis & analysis to feed into policy and service delivery work

NEW AMERICA

What we’re starting to hear*

**All quotes are attributed to an alias assigned to each of our participants to protect their privacy.*

Child care

Child care requires a sacrificial exchange of time, personal goals, and money.

Though parents may receive child care support from family members and government assistance, the additional resources don't fully meet parents' needs.

"It's a struggle finding someone that can take care of the children or pick them up from school. Sometimes there are obstacles. It's not the kids' fault, the obstacles, but you stop doing other things to take care of them."

– Gabriela, Philadelphia mother of 3
(translated from Spanish)

NEW
AMERICA

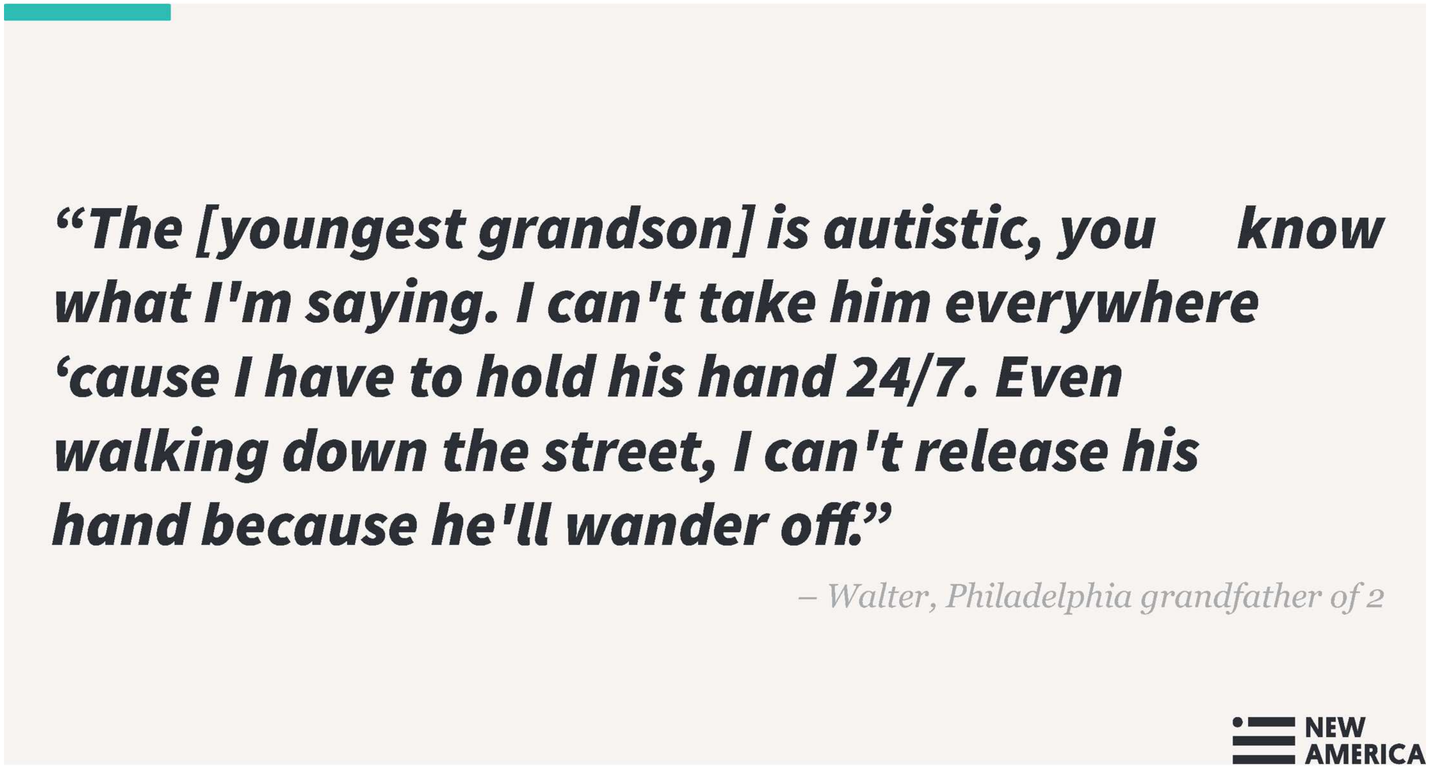
> ***“I know that the government sometimes helps, but sometimes that help is not enough. Because there are a few weeks that I have to overdraw my account to pay for my daughter's day care.”***
>
> *– Lucy, Philadelphia mother of 1*

NEW AMERICA

“Honestly, the only thing I can say that's like stopping me is that I don't really have help with my son. So right now, my big thing is getting him situated. That's something I want to get out the way and then be able to go and follow my dreams... Because I don't have a lot of family living here. I have my mother, but she works a lot.”

– Luna, Philadelphia mother of 1

NEW
AMERICA



> **“The [youngest grandson] is autistic, you know what I'm saying. I can't take him everywhere ‘cause I have to hold his hand 24/7. Even walking down the street, I can't release his hand because he'll wander off.”**
>
> *– Walter, Philadelphia grandfather of 2*

> *[on programs for children, especially those with special health needs]* ***"Sometimes people can't get to those, like different organizations, different places around that area or different states. So I feel like sometimes we should have something within the community, where it's like everybody can make it and everybody can participate"***
>
> *– Keisha, Philadelphia mother of 4 with one on the way*

NEW AMERICA

> ***“[My partner] works Friday through Sunday. So I'm stuck with two children. Like I can't, I can't take a shower. I can't go. I can't do nothing. So I have to hold my bladder until he gets off of work which I normally don't see him into 1:30, 2 o'clock in the morning.”***
>
> *– Charice, Philadelphia mother of 4*

NEW AMERICA

On not visiting the doctor regularly: ***"But when it comes to me, I want to go so bad, but then I'm so lazy. I just don't want to do nothing but relax. Eat four or five bites before the kids get home. But I'm just dead. I know I gotta go do some more tests. And I think I'm gonna do that by next week because the kids are all out of school now."***

– Walter, Philadelphia grandfather of 2

NEW AMERICA

U.S. SENATE SPECIAL COMMITTEE ON AGING

″FROM INFANCY TO AGING: THE EFFECTS OF CAREGIVING ACROSS THE LIFESPAN″

AUGUST 7, 2024

PREPARED WITNESS TESTIMONY

Delilah Picart

Good morning, Chairman Casey. My name is Delilah Picart. I'm from New York City, yet I've called Pittsburgh, PA my home for twenty years. My professional career as a working local actress has allowed me to appear in films and commercials, but currently I have a job I didn't apply for, and I can't quit. I am a caregiver to my brother and mother. I moved them here from East Harlem in April 2023 when it became glaringly apparent that Mom couldn't take care of herself or my brother anymore.

My brother Eric has Fragile X Syndrome and Severe Autism. He is two years younger than me, and I always anticipated taking care of him. My mother Vivian has moderate dementia, and I didn't think I would be taking care of her. My father Enrique died in 2011 from complications of Alzheimer's disease. He was the parent I was most similar to, and the parent I loved most.

I have a complicated relationship with my mother. She believed in tough love parenting, which I have now come to realize is entry-level emotional abuse and manipulation. From six years old to 12 years old, she would threaten to hit me, and often would chase me to my room with a shoe in her hand. She once poured a pitcher of ice water over my head. I was eight years old. When I was a teenager, I would ask her why Eric was different, why did he get special treatment. She mocked me. As I got older still, and with therapy, I realized I didn't like my mother as a person. She was jealous of me and petty. She would gossip. She would criticize me in a spiteful way. We are fundamentally different people. Once, I confronted her about chasing me and scaring me when I was a child. ″You probably deserved it,″ was her retort. I have actively and consciously done all I can to parent my daughter with love and affection.

I would go and visit my mother and brother at least three times a year. Never for more than five days. I couldn't stand her tv addiction, the way she ignored me for the sake of some predictable tv drama. She would answer the phone, ″Not now, Dr. Phil is on,″ then hang up on me. I stopped sharing projects I was working on because I didn't want to hear her criticize and judge me.

Before I moved my family here, I had received a phone call from my mother in July 2022. She said she was having a hard time. She could no longer do simple math. She wanted to get a Power of Attorney. I decided to visit my mother and brother once a month, for a weekend. Over the next four months, I saw my mother sit in her armchair and watch tv all day long. She would forget to take Eric to doctor appointments, neglect to trim his nails. Eric would search the kitchen for food, usually molded bread Mom had hidden from Eric. She no longer cooked; all meals were take-out. Her refrigerator was packed with containers of food, most of it weeks old. She had bags of liquified lettuce, molded vegetables, soft green potatoes, old bags of bacon, and numerous jars of parmesan cheese. She complained that her washing machine no longer functioned, she needed a new one. She had piles of clothes on the floor; she had forgotten if they were clean or dirty. Her pill box was mostly full, she had only taken her medication on Tuesday (it was Friday). She neglected to clean Eric's room. I found it dirty; Eric would purge on whatever food he found and then vomit. Since Mom stopped speaking to Eric, he wouldn't tell her he had made a mess. The four-story, single family brownstone I grew up in had become dark, foul-smelling, dusty, and loud. The volume on the television had the ladies from the View arguing and shouting. It hurt my ears. We signed a POA in New York in November 2022.

By January of 2023, I began visiting twice a month. Mom was becoming aggressive. Eric had dark circles under his eyes. Each trip I would empty out the refrigerator of rotten food. The weekly meal service my fiance' Todd purchased for my family would go unopened and rot. She would sit in her chair and mock me. ″Lilah thinks I have bad food!″ she would proclaim to a visiting neighbor, then throw her head back and laugh. My anger would bubble. I bought fresh fruit and vegetables for my brother. I would prepare dinner in the kitchen and try to salvage a clean plastic container from the closet. Mom would eat a little. She didn't like the vegetarian meals I made. Eric would have seconds. I asked my family members to help pack her up to move, with a target date of August.

I had access to Mom's checking account. One day when I was back home in Pittsburgh, I checked on the accounts, making sure certain bills were paid. There was a debt of $10,000. My stomach knotted. The phone conversation I had with my mother was frustrating and useless. She had no recollection of taking that money out, or where it was. I had visions of a stranger approaching my mother, forcing her to take that money out, or worse, someone mugging her. It was later revealed that she had withdrawn the money from her checking, and quickly deposited it into her Home Equity Loan, which I did not have access to. Within two weeks, I arranged for her and my brother to move out of the brownstone. That was April 2023.

As a caregiver to two individuals with very specific different needs, I am perpetually and eternally exhausted. I am mentally, emotionally, physically, and psychologically tired. I don't have the luxury nor the monetary fluidity to take a break. I had no idea what I was getting myself into when I decided to bring them both here. Yet, I was the only one capable of making a radical change for the betterment of them both. The only one to recognize that my mother had (at the time) undiagnosed dementia, and that my brother was starving and underfed and miserable. Not the nosy neighbors nor her own brother who lived across the street.

As their primary caregiver, I manage their daily care, which includes: pill management (distribution, refill, and pick up); meals (three times a day, seven days a week; five days a week I cook in my house and then pack it and take it over); laundry (once a week, but lately daily [I'll discuss this later]); garbage disposal; transportation (taking Viv to Vintage Senior Center five days a week); dressing (Viv often sleeps in her day clothes); coordination and scheduling of companions; cleaning the apartment (washing dishes, vacuuming, sweeping, bathrooms); grocery shopping as needed (toiletries, paper towels, bath tissue, etc.); scheduling doctors' appointments (quarterly); personal grooming appointments (bi-monthly); bathing reminders.

My family lives in a two-bedroom, two-bathroom apartment four blocks away from my house. It was decided very quickly that they could not move in with me and my fiance' Todd. Mom had difficulty going up and down stairs, and the idea of hearing the tv 20 hours a day; not an option. It was one of my first techniques of self-care: boundaries. Mom had a very hard time adjusting for the first six months. Almost every day, I would arrive in the apartment and find all the items from the kitchen or the linen closet on the dining room table. Sometimes there would be cardboard boxes in the living room. Many times, she would go on Eric's computer tablet and look up ″Man with a Van Pittsberg (sic)″. She was getting calls from neighbors asking her when she was coming back, or saying her phone number was disconnected. She accused me of hijacking her, of trying to kill her. She called me sneaky. Many times, she would call my cell repetitively, six or seven calls withing 10 minutes, yelling into the phone, usually after 10 p.m. I would often power my phone off by 8:30 p.m, another self-care boundary.

I found a woman companion for Vivian. She spends time with her three days a week. I pay her out of pocket. I learned the term ″masking″; a behavior that is practiced by a person with dementia when they are confused by a situation or what is being said to them. They can carry on whole conversations in vague terms because they are cued to react to certain words, tones, mannerisms, and expressions. Vivian gets along beautifully with her companion, and she is well liked at her senior center. I would get the angry Mom, belligerent Mom, mean Mom, usually after 2pm. With the supervision of her Pittsburgh doctor, I got my mother on atypical antipsychotics after she threw a computer tablet at me and missed. It has calmed her down, but it has also given her frequent urination. I threw away all her underwear and she now only wears pull up adult diapers. I say a little mantra before I see my mother now; Grace, Forgiveness, Patience, Acceptance, Compassion, or GFPAC. If I forget a word, I know that's the one I need to focus on with her.

My brother was very happy with the move. He was getting three meals a day and healthy snacks. I introduced him to red peppers and avocado toast and lemonade. He no longer ate whole loaves of bread. He no longer slept in a bed of dried vomit. But I couldn't be with him all day long. Eric was receiving services in NYC, but he was ineligible in Pennsylvania until he had legal residency for six months. Even then, I had to show medical records from over 30 years ago describing and diagnosing his dual disability. By January, he had a very helpful case-worker. His Individualized Support Plan declared him an emergency case because he was living with his mother who was formally diagnosed with moderate dementia.

In the interim, I found a young man to be his companion. Again, I paid out of pocket. They would drive around, listening to music, sometimes going to the museum. When I did have time, we would go to the movies, yet when I brought him home, Mom sometimes had soiled herself, forgetting to get up when she got the urge to use the bathroom. One time I entered the apartment and was met with the smell of something burning. I found two charred eggs in the kitchen trash bin. Mom was hungry, tried to make boiled eggs, forgot the pot on the burner, and had boiled the water to nothing, leaving the eggs to blacken. I removed the pot. Another time, she had made toast only to forget there was a burnt piece already in the slots. I removed the toaster.

Eric and I had a routine. He would greet me in the living room of their sparse apartment. I would apply a nail lacquer to his toenails (he had an untreated nail fungus, something else our mother had neglected) he would wait until ″Kelly and Mark″ tv show, then he would put on his shoes and go downstairs and sit in the lobby. He would people watch most of the morning and some of the afternoon, until Mom would return from the senior center by 2pm. Then, he would wait for me in the lobby. In the Spring, he would be outside, in the green space or on the corner of the church across the street. One day in June, he was behaving in an aggressive manner, acting belligerent and obnoxious. I had never seen or heard Eric behave this way. He started to wander and refused to go into the apartment. This became a weekly behavior. I consulted his doctor and placed him on the same atypical antipsychotic medication that Vivian is on. His behavior is mostly back to normal. As of July 3rd, he now arrives on my porch by 5am. He is wet, because he unfortunately has soiled himself (thus, the daily laundry). After he has changed into clean clothes (I have a few items because of his frequency) we have tea and coffee in my backyard. We make up stories about the birds. Sometimes, we walk my dog, Mango, and count the rabbits. I love my brother immensely.

Eric's sudden unpredictable behavior has made Todd take lead and contact his supports coordinator/case worker. The emphasis of emergency was mentioned again. We finally toured a few respite places for Eric, with the hope of making it residential. Eric is looking forward to the change.

When I am asked, ″How are you?″ I give the rote, safe, bland reply, ″I'm fine, everything is good.″ With my close friends and few family members, I'm honest. I'm sad or angry, or good, in this moment. I'm tissue paper thin. I'm spent. I'm struggling. I just can't today. I wish it would end. I need a change. I'm fortunate; I have a therapist, a support group, a weekly session with a trainer at a gym. Todd takes meals over, my college bound daughter pitches in as asked. I've had a very rich full life with highlights and low points. I watched the Towers fall from two miles away, I've had four car accidents, I've had a stalker terrorize me, and I've had my father go missing for 34 days. This is the most challenging event I've ever experienced.

In an ideal world, caregivers would for receive a public recognition, just like military personnel or EMT. A caregiver would be easily identified on a license. A hotline would be available to answer questions and provide urgent support (i.e., cleaning service, laundry service, meal delivery, companionship). A caregiver would be granted a parking pass to go into the disabled parking spots at the grocery store, hospitals, etc. State programs could provide college credit to graduate students in the social services department, and have said students provide handson companion care to people with intellectual /developmental disabilities. Supplemental income would be provided to caregivers with more than one individual in their care, and requirements would include people with all forms of dementia, not exclusively for people who are incapacitated and home bound. Chefs would be incentivized to prepare healthy meals for people with disabilities and dementia. Service agencies would receive more money to have more staff and more respite housing, so ″emergency″ means immediately, not eight months. Finally, the licensed caregiver could go to a hotel and receive a spa treatment, complimentary dinner, and a few nights in the best room. I would love to have a full night's sleep, and maybe sleep until 7am.

Thank you for your time and attention.

U.S. SENATE SPECIAL COMMITTEE ON AGING

″FROM INFANCY TO AGING: THE EFFECTS OF GIVING ACROSS THE LIFESPAN″

AUGUST 7, 2024

PREPARED WITNESS TESTIMONY

Victoria Snyder

Good morning! I am Tori Snyder, a single mom to a terrific son, Braxton, who is about to start first grade. We live here in Pittsburgh and I'm a proud member of MomsRising.

I want to start by saying thank you, Senator Casey, for organizing this hearing and for all you do to improve support for caregivers. It truly means the world to moms like me. I appreciate the chance to share my family's story.

I am a sandwich generation mom with sole physical and financial responsibility for my son. Over the past several years, I've also provided care for my mother and my late grandmother.

Juggling care for a young child and my aging relatives has been an enormous challenge - financially and emotionally. These challenges are much worse because lawmakers have failed to ensure working people can access paid leave and quality, affordable child care and elder care.

The beginning of the pandemic was an especially hard time for my family. During COVID, Braxton was diagnosed on the autism spectrum. He needs occupational, speech, and behavioral therapy each week. My grandma got COVID and spent months going in and out of the hospital. My mom also spent time in the hospital. I had no money coming in as I lost my job when COVID happened and couldn't even look for a job because I had no one to watch Braxton. It was an extremely scary time, filled with a lot of worries about what tomorrow would bring, because of the unknown, and needing flexibility with my schedule for Braxton's needs, I started a business, Self-Care Senorita, and worked as a small business coach and DEI consultant.

During all this, my biggest fear was what would happen if I got COVID, or worse, an injury that would cause me to not be able to work. I couldn't get sick, and I couldn't get hurt because if I did, I wouldn't be able to work - and then what would happen to my family? Those what-ifs haunted me every day.

Thankfully, Braxton's preschool finally reopened. Having child care again was a relief and allowed me to work more hours, but it cost $800 per month - a big portion of my take-home pay.

Last year, Braxton started kindergarten, and I took a full-time job so he and I could have medical benefits, but I'm still struggling with child care outside of school hours. At first, I tried enrolling him in an after-school program, but that program was expensive and ultimately, we just couldn't afford it. Instead, I interrupt my workday each afternoon to pick him up from school, which is stressful. In order to get my work hours in, I log in before I take him to school, pause, take him to school, work, pause again, get him from school and then work hours in the evenings; it's exhausting trying to manage it all.

My new job also does not provide paid leave. I still worry about what would happen if my mother or son were to be sick. I have to save all of my paid time off for a what-if scenario instead of using it for vacation time with my family or even for my own sick days.

Unfortunately, I know so many parents and caregivers can relate to these challenges. Here in Pennsylvania, about two-thirds of us don't have access to any paid leave through our employers, to care for our kids, ourselves, or our aging loved ones. About 60 percent of us live in child care deserts - and for kids under 5, care costs nearly as much as public college tuition.

These challenges have limited my income and my career opportunities - and I know so many moms who can say the same. When working people like me can't fully utilize our skills, that's bad for businesses and our overall economy.

As I've juggled these responsibilities over the years, I often feel like I'm running in 1,000 directions at once. Sandwich generation caregivers like me are struggling with burnout and exhaustion. I joined MomsRising because I know the only way we'll see progress is if we all raise our voices. I will never stop using my voice to tell lawmakers to invest in the care infrastructure working families need, with paid leave for all, affordable high-quality child care, elder care, and disability care, and an expanded Child Tax Credit. Senator Casey, thank you for having our backs in this fight.

U.S. SENATE SPECIAL COMMITTEE ON AGING

″FROM INFANCY TO AGING: THE EFFECTS OF CAREGIVING ACROSS THE LIFESPAN″

AUGUST 7, 2024

PREPARED WITNESS TESTIMONY

Linda Orndoff

Hello Chairman Casey. My name is Linda Orndoff. I am a home care worker from Coal Center, Pennsylvania. I take care of my elderly mother and my oldest grandson who has autism.

I am a participant-directed home care worker. This means I work directly for my participants, my mother, and my grandson, rather than through an agency. This type of care allows the participant to direct their own care and to choose who works for them. A lot of times, like in our situation, this means family members. They choose people who they know and are comfortable with, rather than whomever an agency sends.

Nevertheless, whether you are participant-directed or an agency worker, doing home care work is a big sacrifice. When I was asked to come here today to speak to you, I was told to just tell my story. I want to share what it is like to be a home care worker, but to make you understand what a home care worker goes through you need to know why the situation is like it is, because of poverty wages and no benefits, we have a huge crisis in the home care industry. Tens of thousands of home care workers must depend on state and federal assistance programs, like food stamps, Medicaid & sometimes cash assistance just to live.

In our country, there is only one caregiver for every six people who need and want care and to make it possible for them to be able to remain in their homes. Without enough home care workers, many people are being forced into nursing homes and assisted living facilities as they cannot find caregivers to keep them at home. In 2021 the annual turnover in the care workforce was 64% and it is only getting worse. It is getting worse because most potential caregivers are unable to do this work when it pays so little and offers no benefits or security.

In my case when my mother and grandson began needing my care full time, I had a big choice to make, put them in a home or quit my job. I chose them. After that, everything about my life changed. When I had to quit my job, I took a huge pay cut and suddenly I had to figure out how to live on poverty wages. I am currently making $13.52, the same hourly wage I made back in the late 80's - early 90's. I could barely live on those wages then, and I certainly can't live on these poverty wages now. When I chose to take care of my family and stop working, I no longer had health insurance, paid sick time, paid vacations, or any retirement benefits.

My mother and grandson depend on my care 10 hours a day, seven days a week. My mother has polycythemia vera which is a rare blood disorder that makes your blood too thick and can lead to strokes and organ damage. She also has chronic kidney disease. She is also senile and has some dementia. She gets angry a lot and is very defiant, mostly towards me. We live in the country, on four acres, and she likes to wander away a lot (mostly tracking her cat). Two summers ago, she disappeared from me, and I couldn't find her anywhere. I was about to call 911 when I heard a noise at the top end of the property. I found her in weeds up to her waist, in bedroom slippers, trying to pull old lumber with rusty nails in it that my brother-in-law had stacked there to burn. Now I have video cameras set up everywhere to track her. Last summer she fell in the front yard about 100 yards from the house, looking for the cat, and she couldn't get up, so she was crawling up through the yard. She lets the cat out the front door and immediately goes to the back door and starts calling her to come in.

My mother likes to get up in the middle of the night and rearrange all the cupboards in the house. Last year when the overflow on the bathroom sink rusted out and started leaking, I told her I was going to have to replace the sink, but she decided it was the drainpipes instead, so she took a hammer and fixed them. Boy did she ever. On top of all of that, she is totally deaf, even with her hearing aids in. This makes communication with her incredibly difficult. I have tried several voice-to-text programs, but they screw up more than they work, so I have to write lots and lots of notes. I could tell you a lot more stories but suffice it to say she keeps me very busy.

In 2014, shortly after I took guardianship of my oldest grandson, he was diagnosed with Asperger syndrome. Asperger syndrome is a previously used diagnosis that is on the autism spectrum. He also suffers from chronic depression and obesity.

In 2019 he and I started a walking program, and he lost over 60 pounds in three months. I was very proud of him.

Unfortunately, my mother's mobile home that they lived in caught fire. It was a total loss. I was able to get them a newer, manufactured home to replace it, but everything was reliant on me and by the time I got everything up to the newer codes and got the house set up and them back home he had put almost all the weight back on. Since then, with my mother's further decline, it has been very difficult for me to be able to leave the house. My grandson's weight has continued to escalate, and I worry every day about his health, which is starting to decline.

I am very active with my union SEIU/United Home Care Workers of PA. In recent years we fought for and won paid training classes for home care workers. These classes teach home care workers CPR and safety training, which I have completed. They also offer classes in working with dementia and autism patients, that I would love to take. I feel they would help me in dealing with the day-to-day tasks of taking care of my mother and grandson. However, these are both 8hour courses and while they are paid training, when you have no one to cover for you it is very difficult to get them done.

As a participant-directed worker, I do not have the same collective bargaining in PA like other workers. This needs to change so we can fully advocate for ourselves. In states where home care workers have collective bargaining, they have won important victories like healthcare and living wages.

Vecause of the workforce crisis in our industry, it is nearly impossible to get backup care. If I get sick there is no one there to take care of them. A couple of years ago when I caught COVID I was completely down for five days. My older sister who can sometimes help me was in Florida on vacation and there was no one to feed my mother or grandson. This year in May I was bit on the neck by a spider. I got very sick for almost a week, but I managed to keep working. I don't have health insurance, so I didn't go to the doctor. After a week I started to get better and then I got sick again. I had a rash on my neck that was spreading that I had attributed to the spider bite. Then the pain started, and it got so bad I went from wondering if I was going to die to hoping that I would. I finally went to a doctor even though I couldn't afford it. I was eventually diagnosed with stage three Lyme disease, but if we had health insurance this never would have progressed to that point.

I would like to be able to tell you, other than the fact that bugs seem to like me, that my story is a unique one, but it is not. In my time in the union, I have spoken to a lot of workers who work 90 and even 100 hours a week. I have listened to the story of a young woman from Philadelphia who after working a full day taking care of her elderly diabetic mother, she then loads her in a car, even in the dead of winter with her blankets and medicines and drives for door dash all night to keep a roof over their heads. I have heard stories from workers who have contemplated suicide from depression over facing eviction from their homes.

We all know home care workers save the system, and taxpayers, tens of thousands of dollars per year caring for folks in their homes over putting them in nursing homes or assisted living facilities, and that these folks have better overall health outcomes, but we need to come up with a plan for how to get caregivers out of poverty. Otherwise, there is no way that we can build a sustainable home-care system, because we can't take care of them if we can't take care of ourselves.

Statements for the Record

U.S. SENATE SPECIAL COMMITTEE ON AGING

″FROM INFANCY TO AGING: THE EFFECTS OF CAREGIVING ACROSS THE LIFESPAN″

AUGUST 7, 2024

STATEMENT FOR THE RECORD

Testimony of American Psychological Association Services

On behalf of the American Psychological Association Services (APA Services), please accept the following written comments for the consideration of the Senate Special Committee on Aging for its Field Hearing titled ″From Infancy to Aging: The Effects of Caregiving Across the Lifespan″. APA Services is the companion organization of the American Psychological Association, which is the nation's largest scientific and professional nonprofit organization representing the discipline and profession of psychology, as well as over 157,000 members and affiliates who are clinicians, researchers, educators, consultants, and students in psychological science. Through the application of psychological science and practice, our organization's mission is to have a positive impact on critical societal issues.

Mental Health Impact of Caregiving

APA Services applauds this Committee's focus on the mental health of caregivers. In 2021, an estimated 38 million family caregivers provided some form of unpaid care to an adult experiencing permanent or temporary limitations in their ability to perform everyday activities of living like mobility, eating, or bathing.[1] The specific nature of the assistance furnished by caregivers varies by the nature and degree of the person's condition.[2] For example, individuals recently discharged from hospital settings may need caregivers to assist with adherence to post-discharge protocols like medication or diet. Older adults are also more likely to experience conditions that result in fluctuating and potentially diminished capacity for decision making, namely post-operative delirium and other neurocognitive disorders, which can necessitate caregiver assistance with daily activities including managing finances or use of prescription medications. Those with disabilities may require caregivers to assist with various activities of daily living (ADLs) or transportation. People with serious mental health needs may require caregivers to monitor their well-being and safety. In addition to these direct care tasks, many caregivers also assume a care coordination role that could include addressing problems with health insurance coverage or communicating with multiple providers about implementing plans of care.

Through their unreimbursed efforts, caregivers contribute a total of approximately $600 billion to the U.S. health care system. However, the fact that a caregiver provides services to a loved one without expectation of compensation does not mean that caregiving is entirely ″free.″ Indeed, there is ample evidence of its physical and mental toll on caregivers. Caregiving is generally associated with higher levels of risk for chronic health conditions like coronary heart disease,[3] increased inflammation,[4] and accelerated aging of the caregiver's immune system.[5] There is also evidence that caregivers are generally more likely to neglect their own health and forego preventative care for their own medical needs.[6]

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[1] AARP Public Policy Institute (March 2023). Valuing the Invaluable: 2023 Update. https://www.aarp.org/content/dam/aarp/ppi/2023/3/valuing-the-invaluable-2023-update.doi.10.264192Fppi.00082.006.pdf.

[2] Reinhard, Susan, Heather M. Young, Carol Levine, Kathleen Kelly, Rita Choula, and Jean Accius. Home Alone Revisited. Washington, DC: AARP Public Policy Institute, April 2019 https://doi.org/10.26419/ppi.00086.001.

[3] Haley WE, Roth DL, Howard G, Safford MM. Caregiving strain and estimated risk for stroke and coronary heart disease among spouse caregivers: differential effects by race and sex. Stroke. 2010 Feb;41(2):331-6. doi: 10.1161/STROKEAHA.109.568279. Epub 2010 Jan 14. PMID: 20075357; PMCID: PMC2818824.

[4] Allen A. P., Curran E. A., Duggan A., Cryan J. F., Chorcorain A. N., Dinan T. G., . Clarke G (2017). A systematic review of the psychobiological burden of informal caregiving for patients with dementia: Focus on cognitive and biological markers of chronic stress. Neuroscience and Biobehavioral Reviews, 73, 123-164. doi:10.1016/j.neubiorev.2016.12.006

[5] Mausbach, B. T., Patterson, T. L., Von Kanel, R., Mills, P. J., Dimsdale, J. E., Ancoli-Israel, S., & Grant, I. (2007a). The attenuating effect of personal mastery on the relations between stress and Alzheimer caregiver health: A five-year longitudinal analysis. Aging & Mental Health, 11, 637-644.

[6] Schulz, R., Newsom, J., Mittelmark, M., Burton, L., Hirsch, C. & Jackson, S. (1997). Health effects of caregiving: The Caregiver Health Effects Study: An ancillary study of The Cardiovascular Health Study. Annals of Behavioral Medicine , 19, 110-116.

The mental health impacts of caregiving tell a similar story. While caregivers may experience some degree of personal psychological fulfillment and meaning through their efforts,[7] caregivers also are more likely to report higher levels of anxiety and depression than their non-caregiver counterparts.[8] In addition to the obvious physical and mental strain from providing direct support, caregivers experience additional stressors that can contribute to this phenomenon. With 61% of caregivers under employment, caregivers may experience stress from balancing their work-related demands with those at home.[9] Caregivers may also be struggling with balancing care for the older adult with caring for other family members, as 30% of caregivers reside in multi-generational households with children or grandchildren.[10] Caregivers for patients with dementia, for example, may be coping with their own sense of anticipatory bereavement of losing their loved one or a deterioration of the relationship due to any cognitive or behavioral manifestations of the disease.[11]

Evidence-Based Caregiver Training

Caregivers are rarely, if ever, asked whether they are prepared for their new caregiving role. Instead, they are frequently thrust very quickly into caregiving situations with little notice and limited training as to the complicated tasks they are expected to perform as part of this role. Unfortunately, this lack of mastery of caregiving tasks only serves to amplify the anxiety and depression that caregivers may already be experiencing.[12]

Caregiver Behavior Management Training (CBMT) helps fulfill this unmet need of caregivers. CBMT is provided to parents or caregivers of multiple patients simultaneously, teaching interventions that caregivers can independently use to better manage the patient's disease. Behavioral training associated with this service requires the clinical expertise of at least one psychologist or qualified health care professional (QHP) who is well versed in evidence-based behavior management procedures and strategies.

This has the effect of multiplying the impact of treatment, serving more individuals while utilizing fewer clinical hours. In other words, more patients are helped by fewer providers over less time when compared to individual or family therapy treatment sessions. For example, providing a 60-minute group caregiver behavior management service for five patients over twelve sessions would result in 720 minutes of direct patient care, compared to treating five patients with family therapy for 12 sessions, which would result in 3,600 minutes of direct patient care. This efficiency improves access to care for patients and ultimately results in cost savings for the health care system.[13] These services are also known to delay the necessity of nursing home placements for older adults with dementia, allowing patients to remain in their own homes over a longer span of time.[14]

APA Services applauds the Centers for Medicare and Medicaid Services (CMS) for activating a new coding and reimbursement mechanism for CBMT services provided by psychologists and other QHPs (CPT Codes 96202/96203) in its annual Medicare Physician Fee Schedule proposed rule. APA Services also applauds CMS for allowing such services to be furnished via telehealth, enabling access for the many caregivers who cannot travel to an in-person clinical setting due to their own or the patient's circumstances. APA Services calls on members of the Committee to support

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[7] Miller, B. Adult Children's Perceptions of Caregiver Stress and Satisfaction. Journal of Applied Gerontology 8, no. 3 (1989): 275-93

[8] Beach, S. R., Schulz, R., Yee, J. L., & Jackson, S. (2000). Negative and positive health effects of caring for a disabled spouse: Longitudinal findings from the Caregiver Health Effects Study. Psychology & Aging, 15 (2), 259-271.doi:10.1037//0882-7974.15.2.259.

[9] AARP and National Alliance for Caregiving. Caregiving in the United States 2020. Washington, DC: AARP. May 2020. https://doi.org/10.26419/ppi.00103.001

[10] Id.

[11] Ascher EA, Sturm VE, Seider BH, Holley SR, Miller BL, Levenson RW. Relationship satisfaction and emotional language in frontotemporal dementia and Alzheimer disease patients and spousal caregivers. Alzheimer Dis Assoc Disord. 2010 Jan-Mar;24(1):49-55. doi: 10.1097/WAD.0b013e3181bd66a3. PMID: 20220322; PMCID: PMC2838197.

[12] Chan EY, Glass G, Chua KC, Ali N, Lim WS. Relationship between Mastery and Caregiving Competence in Protecting against Burden, Anxiety and Depression among Caregivers of Frail Older Adults. J Nutr Health Aging. 2018;22(10):1238-1245. doi: 10.1007/s12603-018-1098-1. PMID: 30498832; PMCID: PMC6302747.

[13] Sansoni, J., Anderson, K. H., Varona, L. M., Varela, G. (2013). Caregivers of Alzheimer's patients and factors influencing institutionalization of loved ones: some considerations on existing literature. Annali di Igiene: Medicina Preventiva e di Comunita, 25(3), 235-46. doi: 10.7416/ai.2013.1926. PMID: 23598807

[14] Mittelman, M. S., Haley, W. E., Clay, O. J., Roth, D. L. (2006). Improving caregiver well-being delays nursing home placement of patients with Alzheimer disease. Neurology, 67(9), 1592-9. doi: 10.1212/01. wnl.0000242727.81172.91. PMID: 17101889.

this proposed rule and to facilitate similar coverage of these services in Medicaid and Marketplace plans.

Prompt Access to Evidence-Based Treatment

Of course, adequate training will not entirely eliminate the need for individual mental or behavioral health care for some caregivers. Congress must make it a priority to facilitate access to mental and behavioral health services for caregivers and other individuals who may be struggling with an unmet mental or behavioral health need. The acceptance and use of telehealth (including telehealth furnished via audioonly interactions) for treatment of mental and behavioral health services, for example, remains a popular option for patients and practitioners alike.[15] In some cases, the decision of patients and providers to use telehealth may have superior clinical benefits over their in-person counterparts; for example, psychologists treating patients via telehealth may gain insights into the patient's personal living environment or patients may feel more comfortable accessing treatment from the comfort and safety of their own homes.

Congress is faced with critical decisions before the end of this year on whether to continue this forward momentum on access to tele-mental and tele-behavioral services. Fortunately, Congress decided to permanently allow Medicare beneficiaries to receive mental health services via telehealth from their own homes in the Consolidated Appropriations Act of 2021; however, it also imposed a requirement that Medicare beneficiaries must be seen in-person by the provider for continued coverage of their telehealth services.

Congress should reconsider and repeal the ″in-person visit″ requirement. Patients seeking mental health services already face several obstacles to treatment, including but not limited to social stigma, complicated insurance coverage policies, and practical difficulties like transportation. Imposing an arbitrary and uniform in-person visit requirement increases the likelihood that patients will simply discontinue treatment altogether. Rather than discouraging fraudulent claims, this policy will instead discourage many more legitimate claims for treatment. Additionally, the fact that the in-person visit only applies to mental health services further perpetuates a bias against coverage of mental and behavioral health treatment in Medicare and other insurance coverage programs.

APA Services calls on members of the Committee to adopt a permanent solution, such as the Telemental Health Care Access Act (H.R. 3432), that would ensure Medicare beneficiaries' continued access to the broad range of mental and behavioral health services via telehealth without unnecessary and arbitrary barriers to treatment. Given the political dynamics of a Presidential election year, however, we understand that Congress may need additional time to make this decision. APA Services acknowledges that a twoyear extension of the current Medicare coverage rules, such as that offered in the Energy & Commerce Committee's forthcoming markup of the Telehealth Modernization Act (H.R. 7623), may be necessary as a short-term solution. However, we ask Congress to make a longer-term decision by the end of that extension; patients require stability in their ability to access mental and behavioral health treatment remotely.

There are also innovative and evidence-based models of integrating behavioral health treatment into primary care practices, such as the Primary Care Behavioral Health (PCBH) model and the Collaborative Care model (CoCM), as well as models that blend different features of PCBH and CoCM based on the resources available in their local community. There is ample evidence that integrated care can result in cost savings across the health system, since behavioral comorbidities can lead to medical costs for physical conditions that are two to three times higher than incurred for patients without behavioral health conditions.[16] These benefits are especially felt in rural and underserved areas where the local primary care clinic is the default health care system. However, despite its potential, a number of barriers

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[15] See, e.g., Bartelt K, Piff A, Allen S, Barkley E. Telehealth Utilization Higher Than Pre-Pandemic Levels, but Down from Pandemic Highs. Epic Research. https://epicresearch.org/articles/telehealth-utilization-higher-than-prepandemic-levels-but-down-from-pandemic-highs. Accessed on July 12, 2024.

[16] See, e.g., Ross, K. M., Klein, B., Ferro, K., McQueeney, D. A., Gernon, R., & Miller, B. F. (2019). The cost effectiveness of embedding a behavioral health clinician into an existing primary care practice to facilitate the integration of care: A prospective, case-control program evaluation. Journal of Clinical Psychology in Medical Settings, 26, 59-67 (finding that integrating a psychologist into a primary care practice resulted in cost savings of $860 per member per year).

exist to practitioner adoption of integrated care.[17] These include additional clinical and administrative staffing costs, adequate reimbursement for increased interprofessional consultation, education, and training, changes to primary care practices' operating procedures, upgrades or modifications to physical office spaces, and investments in information technology systems.

To help practitioners overcome these barriers, APA Services urges members of this Committee to support the **COMPLETE Care Act (H.R. 5819/S. 1378).** This bill would temporarily boost Medicare reimbursement rates for certain integrated care codes to aid in the up-front adoption costs, require CMS to provide technical assistance to primary care practices seeking to adopt evidence-based behavioral health integration models, and require CMS to establish quality measurement reporting requirements for behavioral health integration services within existing Medicare alternative payment models. Last December, the Senate Finance Committee voted 26-0 to approve key provisions of the COMPLETE Care Act as part of the Better Mental Health Care, Lower-Cost Drugs, and Extenders Act of 2023.

Robust Support for Key Caregiving Programs

Many federal programs provide a key supplement to services provided by clinicians. Area Agencies on Aging (AAAs) and Aging and Disability Resource Centers (ADRCs) serve as a critical hub for services to older adults and adults with disabilities. For example, the National Family Caregiver Support Program provides grant funding to an array of supports to caregivers-including those that are non-clinical in nature. Services commonly provided under this program include information about services available to caregivers in the community, navigation to accessing these services, individual caregiver counseling (including support groups and caregiver training), and temporary respite care. However, important programs like this are set to expire at the end of the current fiscal year due to the expiration of the Older Americans Act. APA Services calls on members of this Committee to support a robust reauthorization of this critical piece of authorizing legislation.

Further research is also a necessary means of developing new innovations in caregiver support. The National Institute on Aging (NIA) was founded in 1974 within the National Institutes of Health (NIH) to support research on the health of older adults. NIA-supported research provides the foundation for scientific advancements in the field of gerontology, including family caregivers' contributions. Funding for key research at NIA would include research on caregivers' needs and how best to address issues specific to caregivers. APA Services asks members of this Committee to continue its support for robust funding of NIH at $51.303 billion for FY 2025 and commensurate increases in NIA funding.

APA Services appreciates the Committee's efforts to ensure that the invaluable efforts of caregivers are not lost due to physical or mental health challenges. We are eager to work with this Committee and its members to develop legislation that would accomplish this goal.

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[17] Hartnett, T., Loud, G., Harris, J., Curtis, M., Hoagland, G.W., Serafini, M., Glassberg, H., Chung, H. (2023). Strengthening the Integrated Care Workforce. Bipartisan Policy Center. https://bipartisanpolicy.org/report/strengthening-the-integrated-care-workforce/

U.S. SENATE SPECIAL COMMITTEE ON AGING

″FROM INFANCY TO AGING: THE EFFECTS OF CAREGIVING ACROSS THE LIFESPAN″

AUGUST 7, 2024

STATEMENT FOR THE RECORD

Testimony of MomsRising

I am Karen Showalter, Pennsylvania Moms Force Director for MomsRising, the online and on-the-ground organization of more than one million mothers and their families, including over 25,000here in Pennsylvania, working to improve family economic security, stop discrimination against women and moms, and build a nation where businesses and families can thrive.

Pennsylvanians applaud Senator Bob Casey for holding today's field hearing in Pittsburgh, ″Family Caregiving Across the Lifespan.″ This hearing underscores the Senator's longstanding commitment to hearing directly from working families about the most pressing challenges they face because our country has failed to invest in common-sense care infrastructure policies. Addressing these challenges is essential to our State's and our country's success, and we are grateful for Senator Casey's work to shine a light on the urgent need to invest in care.

At MomsRising, we know that care work, whether it's paid or unpaid, powers our economy. Care work is the work that makes all other work possible, but unfortunately, in our country today, too often care work is undervalued, underpaid and unsupported. That has to change if we are to build a thriving economy that works for working families.

Building a care infrastructure is a top priority for MomsRising because it is a top priority for our members, who tell us every day that their families are struggling without paid leave, access to high-quality, affordable child care, elder and disability care, and more.

The challenges are immense. Right now in Pennsylvania and across the country, most working people have no access to any paid leave through their employers. That means zero paid leave to welcome a new baby, zero paid leave to care for a loved one who needs surgery, and zero paid leave to seek care after a cancer diagnosis. In those moments, the last thing anyone should have to worry about is how they will keep their job or pay their bills, but without paid leave, those worries are life-shaping for hardworking people with new babies or health emergencies.

For example: Nancy is a MomsRising member in the Philadelphia area who works in retail, sometimes working 50 hours/week. She also cares for her aging father, taking him to doctor's appointments, keeping his home in order, and ensuring his basic needs are met. Without paid leave, she is forced to squeeze her caregiving responsibilities into non-working hours. If her dad has an emergency, she loses pay, making it harder to pay the bills. Nancy told us, ″Paid leave would mean so much for his care, our relationship, and my body/mindset. I feel exhausted and stressed every single day.″

If Congress were to pass the FAMILY Act, guaranteeing 12 weeks of comprehensive paid leave for all workers, it would make an enormous difference for Nancy and millions of caregivers like her.

At MomsRising, we also hear from members about the stresses and challenges they're facing because of our country's child care crisis. Parents are trying their best, but struggling with high costs and low availability. On the other hand, child care workers, the majority of which are women and mothers, are struggling to support their own families with low wages and scant or no benefits.

All kids deserve high-quality early learning opportunities, and when parents can't find or afford the child care they need to hold jobs and provide for their families, it doesn't just hurt families - it causes immense harm to businesses and our economy.

We lose out on the skills of parents like Stefanie, a MomsRising member in Palmyra. Stefanie earned a master's degree and used to work in a hospital lab, but when COVID hit, she had to leave her job because child care wasn't available. Recently, she was contacted about a job opportunity, but when she looked into child care, she found that care for her three young children would cost her family more than $4,000 a month, and that it would take months if not years to get off the waitlist, making the ability to even find child care in time unlikely.

Families face similar challenges finding affordable elder and disability care, because of decades of underinvestment, MomsRising members tell us finding home- and community-based support for aging parents or loved ones with disabilities is like trying to find a needle in a haystack. By and large, care workers of all kinds aren't paid what they deserve. That's led to workforce shortages, making it even harder for families to find the support they need.

For sandwich generation caregivers, these issues intersect and compound - and the number of sandwich generation caregivers is growing. As of 2018, more than eight million people nationwide were providing unpaid care for an adult, such as an aging parent, while also caring for a child under 18. By 2060, the number of adults over age 65 is expected to double compared to what it was in 2016.Whether or not we choose to invest in care now will determine whether we can meet that challenge. Just like we need to build bridges and roads to drive on to get to work - we need care infrastructure so parents can go to work, so kids can thrive, and so care workers can earn living wages - and we need a path to citizenship for immigrant care workers.

That's why MomsRising is building a broad coalition of parents, caregivers, care workers, and business leaders to fight for the care agenda. The good news: These policies are enormously popular. In a recent poll MomsRising commissioned with the National Women's Law Center, voters across the spectrum voiced **strong support** for raising taxes on the wealthiest individuals and corporations to fund federal investments in care.

We are enormously grateful for leaders like Senator Casey who are working to make those investments a reality, and for all of the panelists who shared their perspectives at today's field hearing. Together, we can build the care infrastructure that will make it possible for our country's children, families, communities, businesses and economy to thrive.

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