

Testimony of Alison Barkoff, J.D.

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For

“Aging in Place: The Impact of Community During the Holidays”

Senate Special Committee on Aging Hearing

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

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

Preference for and Benefits of Community Living

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

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

There has been strong bipartisan support for policies, programs, and services that help older adults and people with disabilities live in the community and age in place, such as the Older

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

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

³ <https://acl.gov/about-community-living>

⁴ <https://acl.gov/about-community-living>

⁵ See *Olmstead v. L.C.*, 527 U.S. 581 (1999); https://archive.ada.gov/olmstead/olmstead_about.htm; <https://www.ada.gov/topics/community-integration/>

Americans Act (OAA) programs and the Money Follows the Person program that helps people transition from nursing homes back to the community. The demand for community living is expanding exponentially, with more than 10,000 people turning 65 every day and a growing population of disabled people living longer (often with aging caregivers).⁶

Supporting Older Adults and People with Disabilities in the Community

Medicaid-funded Home and Community-Based Services

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

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

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

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

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

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

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

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

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

Older Americans Act Programs

The OAA funds a range of community-based services to help older adults, including older adults with disabilities, age in place, maintain their health, and engage in their communities. This includes personal care services, respite, transportation, family caregiver supports, and senior nutrition programs. OAA programs support one in five Americans over 60.¹²

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

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

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

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

Independent Living and Other Disability Programs

Independent living programs, authorized and funded under the Rehabilitation Act, help support disabled people of all ages to live, work, and participate in their communities. Local Centers on Independent Living (CILs) provide a wide range of supports, including assistance to people at risk of entering or transitioning from institutions to the community, training on independent living skills, transportation, and assistance with finding a job or housing.¹⁵ Other programs funded under the Developmental Disabilities Act, including State Councils on Developmental Disabilities,¹⁶ Protection and Advocacy Systems,¹⁷ and University Centers on Excellence in

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

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

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

¹⁵ https://acl.gov/sites/default/files/programs/2023-12/CIL_FactSheet_2023.508.pdf

¹⁶ https://acl.gov/sites/default/files/programs/2023-12/DDCouncils_FactSheet.508.pdf

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

Developmental Disabilities,¹⁸ help people with intellectual and developmental disabilities and their families in accessing community-based services. As with OAA programs, demand outpaces growing need; continued investment in these programs is essential to supporting the growing population of disabled people, including those aging with and into disability.

Affordable Accessible Housing

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

Multisector Plans to Support Community Living

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

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

The Administration for Community Living (ACL) plays a critical role in helping older adults and people with disabilities live and participate in their own communities and age in place. ACL is the only federal agency focused on community living, elevating the issue and ensuring that older

¹⁸ https://acl.gov/sites/default/files/programs/2023-12/UCEDD_FactSheet_2023.508.pdf

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

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

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

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

²³ <https://multisectorplanforaging.org/>

adults and disabled people are considered in federal policies across the Department of Health and Human Services (HHS) and the federal government.

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

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

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

²⁴ <https://acl.gov/programs/aging-and-disability-networks>

²⁵ <https://acl.gov/ncsc>

²⁶ <https://acl.gov/DCWcenter>

²⁷ <https://acl.gov/HousingAndServices>