

JUSTICE IN AGING

FIGHTING SENIOR POVERTY THROUGH LAW

March 21, 2022

Senator Bob Casey
Chairman
U.S. Senate Special Committee on Aging

Senator Tim Scott
Ranking Member
U.S. Senate Special Committee on Aging

Via email: SFR@aging.senate.gov

RE: March 23, 2022 Hearing on “An Economy That Cares: The Importance of Home-Based Services”

This statement is submitted on behalf of Justice in Aging, an advocacy organization with the mission of improving the lives of low-income older adults. We use the power of law to fight senior poverty by securing access to affordable health care, economic security, and the courts for older adults with limited resources. We have decades of experience with Medicaid and Medicare benefits, with a focus on the needs of low-income beneficiaries and populations that have traditionally lacked legal protections such as women, people of color, LGBTQ individuals, people with disabilities, and people with limited English proficiency.

Justice in Aging advocates to improve our long-term care system, including access to Medicaid home- and community-based services (HCBS). We provide training and technical assistance to attorneys, aging network professionals, and other advocates from across the country on how to address problems that arise under Medicare and Medicaid, and engage with the Centers for Medicare and Medicaid Services and policymakers to ensure older adults can access the long-term services and supports they need to age with dignity.

We appreciate you holding this very timely hearing on the importance of home-based services. The COVID-19 pandemic has taken the lives of more than 200,000 older adults, people with disabilities, and staff living and working in long-term care facilities, making access to home-based services, and a well-paid and respected workforce, more important than ever.

Most Americans intuitively understand the desire to live at home throughout our lives and as we age. But for so many people, especially people with low income and wealth, this is not a choice they ever get to make for themselves. The historic and persistent underfunding of our

Washington, DC



Los Angeles, CA



Oakland, CA

Medicaid HCBS system and barriers to aging in place are the direct result of our ageist, ableist, and racist systems.

[Over one-third of adults age 65 and older have some form of disability](#) and many need assistance with daily activities such as bathing, eating, toileting, housework, medication management, financial management, and grocery shopping.ⁱ [In 2019](#), 40% of older adults reported difficulties with mobility, 9% had difficulties with self-care, 27% had difficulties with cognition.ⁱⁱ The proportion of people with disabilities and need for assistance increases with age.

Medicaid HCBS is the only program that covers the full range of support older adults with disabilities need to remain safely in their own homes and connected to their communities. However, due to the institutional bias in federal Medicaid law, states are required to cover nursing facility and other long-term institutional services but they are not required to cover the full range of HCBS to meet the needs of people with disabilities, including older adults, in the community. This bias means that an older adult who needs support with activities of daily living can enter a nursing facility tomorrow but often has to wait years for HCBS. If they do not have loved ones to care for them while they wait or cannot pay out of pocket for help, the nursing facility becomes the only option. It also makes it very difficult for someone who is in an institutional setting to return home because they may not be able to get the help they need to do so safely.

While progress has been made to expand access to HCBS over the years, [half of states still spend twice as much on institutional care as they do on HCBS for older adults](#).ⁱⁱⁱ Unfortunately, this inequity is even worse in some states. For example, Iowa is spending nine times more on institutional care than on HCBS for older adults. In Florida, 50,000 older adults are waiting years to become eligible for HCBS.^{iv}

Not only does it matter where you live, but access to HCBS also depends on what disabilities and chronic conditions you have. At age 80, [75% of older adults with Alzheimer's and dementia are living in nursing homes](#) compared to just 4% of the general population. Two-thirds of those who die of dementia are doing so in nursing homes.^v

In addition, people with lower incomes, especially older adults who live alone, are more likely to be in a nursing home. This coincides with the [growing number of older adults who are unhoused](#) and who face the ultimate barrier to accessing HCBS.^{vi}

These geographic, disability, and socioeconomic inequities intersect with race-based disparities, resulting in greater inequities in access to HCBS for people of color. For example, compared to white older adults, [Black older adults are nearly twice as likely, and Hispanic older adults are nearly 1.5 times as likely, to have Alzheimer's and other dementias](#).^{vii} In addition, [older adults of color are being admitted to nursing homes at higher rates](#) than white older adults in part, researchers suspect, due to the lack of HCBS options.^{viii}

The tolls of the underinvested HCBS system also fall on families who fill in the gaps by leaving the workforce or reducing their hours to provide care that is unpaid. This underinvestment drives both short and long-term financial insecurity for millions of families, and particularly women of color. For example, recent studies found that Black family caregivers are more likely to [provide in excess of 40 hours of care per week](#)^x to older adults who have more extensive care needs and limited financial resources but are [less likely to use respite](#) than white family caregivers.^x

To begin to address these inequities and ensure that older adults in every state and every community can make the choice to age in their own homes and communities, we need a transformative investment in Medicaid HCBS. The Better Care Better Jobs Act offers this solution by providing states with sustainable funding to build the necessary HCBS infrastructure, grow a well-compensated workforce, and allow family caregivers to return to their jobs. This legislation would also take steps to address the institutional bias by permanently extending spousal impoverishment protections to people who need HCBS and by making the Money Follows the Person program permanent.^{xi} These policies are critical to avoiding institutionalization and being able to return to community-based settings.

We urge the Senate to pass this investment as soon as possible so that states can continue the work they have begun with American Rescue Plan funding, and so older adults and people with disabilities can access high-quality HCBS when they need it.

Thank you again for holding this hearing and for the opportunity to provide input. Should any questions arise, please reach out to Natalie Kean, Senior Staff Attorney for Federal Health Policy, at nkean@justiceinaging.org, or myself at achrist@justiceinaging.org.

Sincerely,



Amber Christ
Directing Attorney of Health Advocacy & Policy

ⁱ Administration for Community Living, “2019 Profile of Older Americans,” May 2020, available at <https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/2019ProfileOlderAmericans508.pdf>.

ⁱⁱ Administration for Community Living, “2020 Profile of Older Americans,” May 2021, available at <https://acl.gov/sites/default/files/Aging%20and%20Disability%20in%20America/2020ProfileOlderAmericans.Final.pdf>.

ⁱⁱⁱ Justice in Aging, “Medicaid Home and Community-Based Services for Older Adults with Disabilities: A Primer,” April 2021, available at <https://justiceinaging.org/wp-content/uploads/2021/04/HCBS-Primer.pdf>. See also, Centers for Medicare & Medicaid Services, “Medicaid Long Term Services and Supports Annual Expenditures

Report FY 2017 and 2018,” Jan. 2021, available at <https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/ltssexpenditures-2017-2018.pdf>.

^{iv} Id.

^v Alzheimer’s Association, “2022 Alzheimer’s Disease Facts and Figures,” January 2022, available at <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>.

^{vi} Justice in Aging and National Low Income Housing Coalition, “Low-Income Older Adults Face Unaffordable Rents, Driving Housing Instability and Homelessness,” Feb. 2021, available at <https://justiceinaging.org/wp-content/uploads/2021/02/Older-Adults-Rental-Housing-Burdens.pdf>.

^{vii} Alzheimer’s Association, “2022 Alzheimer’s Disease Facts and Figures,” January 2022, available at <https://www.alz.org/media/Documents/alzheimers-facts-and-figures.pdf>.

^{viii} Health Affairs, “Growth of Racial and Ethnic Minorities in US Nursing Homes Driven by Demographics and Possible Disparities in Options,” July 2011, available at <https://www.healthaffairs.org/doi/abs/10.1377/hlthaff.2011.0126>.

^{ix} Gerontologist, “Race Differences in Characteristics and Experiences of Black and White Caregivers of Older Americans,” Sep. 2020, available at <https://pubmed.ncbi.nlm.nih.gov/32400881/>.

^x Journal of Aging Health, “Racial Differences in Respite Use among Black and White Caregivers for People Living with Dementia,” Dec. 2020, available at <https://pubmed.ncbi.nlm.nih.gov/32819177/>.

^{xi} Justice in Aging, “Make the Expanded Spousal Impoverishment Protection Permanent,” Jan. 2019, available at <https://www.justiceinaging.org/wp-content/uploads/2019/01/Justice-in-Aging-Federal-Spousal-Impoverishment-Fact-Sheet-11-8-18.pdf>.