

# Policy Priorities to Increase Equitable Access to Home-Based Care

JANUARY 2023

## About Justice in Aging

Justice in Aging is a national nonprofit organization that uses the power of law to fight senior poverty by securing access to affordable health care and economic security for older adults with limited resources. We focus our efforts on fighting for people who have been marginalized and excluded from justice, such as women, people of color, LGBTQ+ individuals, people with disabilities, and people with limited English proficiency. We are committed to advocacy to address the long-standing, pervasive, ongoing, systemic racism that infects our culture, government, and systems of power.

We are asking Congress and the Biden-Harris Administration to prioritize policies that enable older adults and people with disabilities with limited income and resources have access to the support they need to remain living in their homes and communities. Medicaid home and community-based services (HCBS) is the primary—and in many cases only—means for accessing at-home care. But the HCBS infrastructure is not able to meet current and growing needs due to underinvestment and policy biases towards institutional care.

Every day, 10,000 people turn 65, and by 2050, older adults over 65 will double and older adults over 85 will triple. Over half of older adults will develop a disability that will require long-term services and supports (LTSS) to help with activities of daily living such as bathing, dressing, and eating. Due to compounding inequities over the lifespan, greater percentages of older adults of color have disabilities, and at younger ages. Overwhelmingly, older adults prefer to live in their own homes where they can stay connected to their community. And COVID-19 continues to put residents in congregate care settings at grave risk for serious illness and death, with facilities that have more residents of color at highest risk. Yet, too many older adults with limited resources are forced into institutional settings to receive the care they need, particularly women, people of color, LGBTQ+ older adults, and individuals with Alzheimer's or other dementias. While nursing home use has steadily been declining among white older adults, use has increased among Hispanic, Asian, and Black older adults, in part due to the fact that communities of color have less access to HCBS.

To increase equitable and quality access to HCBS, Congress must make bold investments in the HCBS infrastructure and take steps to end federal Medicaid and Medicare laws' biases towards institutional services. The Administration must uplift HCBS and community integration as a priority across all divisions of Health and Human Services and increase coordination with Housing and Urban Development and other agencies. We look forward to working with Congress and the Administration to implement the HCBS priorities listed below.

## Invest in HCBS Infrastructure

The enhanced federal funding Congress provided to states through the bipartisan American Rescue Plan Act (ARPA) was essential to mitigate the worst harms of the COVID-19 pandemic. Every state accepted this funding and most used it to support the direct care workforce and prevent cuts to HCBS. To ensure states can build on this

foundational work, Congress must provide long-term enhanced federal funds to enable states to build a stronger HCBS infrastructure that addresses unmet need and prepares for the future. This investment is necessary to support the people doing direct care work and family caregivers, to increase access to HCBS for older adults and people with disabilities of all ages in every state and territory, and to end disparities in HCBS access that people of color and other marginalized communities experience. The Centers for Medicare & Medicaid Services (CMS) can also take steps to support states and territories in enhancing their HCBS infrastructure.

- Congress must deliver long-term federal funding through an enhanced Federal Medicaid Assistance Percentage (FMAP) dedicated to supporting and growing the direct care workforce and increasing equitable access to HCBS.
- Congress should expand the mandatory HCBS state plan benefits and require all states to cover personal care and respite services for all populations.
- CMS should work with states to maximize the longevity of ARPA funding initiatives and support new states and territories to take up existing HCBS expansion options, such as Community First Choice and Money Follows the Person.
- Congress must invest in affordable and accessible housing and public housing programs. CMS should encourage and incentivize states to [expand access to housing-related services through Medicaid](#) and increase access to HCBS for individuals experiencing homelessness.
- Congress and CMS should enhance LTSS demographic data collection requirements, provide support for states to collect data, and conduct thorough oversight to better understand who has access to HCBS and who does not. Data collection should include race, ethnicity, primary language, age, disability status, sex, gender identity, and sexual orientation and allow for intersectional analysis. This information should be presented in a user-friendly and accessible format and used to deploy targeted strategies to ensure equitable access, quality, and utilization of HCBS.

## Support Policies that Help People Avoid Institutions and Return to the Community

Both Congress and the Administration should work across Medicare and Medicaid to implement strategies to transition older adults and people with disabilities out of institutional settings and, equally as important, divert their initial admission, particularly when being discharged from the hospital or post-acute care.

- Congress must make permanent the [Medicaid Money Follows the Person Program](#) and [protections from impoverishment for spouses of people eligible for HCBS](#). CMS should work with all states and territories to implement or expand the MFP program, including the MFP Tribal Initiative, and properly implement the spousal impoverishment protections.
- CMS and Congress should enable older adults and people with disabilities to promptly access HCBS, as soon as the need arises, by [ensuring retroactive Medicaid coverage is available for HCBS](#), as it already is for nursing facility coverage.
- CMS and Congress must provide safeguards to prevent improper terminations for Medicaid enrollees once the public health emergency ends so that people with disabilities do not lose access to HCBS. This includes requiring ex parte renewals for people eligible based on age or disability, providing significant time and support for redeterminations to be completed, and making permanent certain emergency flexibilities under Appendix K emergency waivers, including payments to family caregivers.
- Congress should increase the allowance for home maintenance so that older adults and people with disabilities can afford to maintain their home or apartment during short-term stays in nursing facilities and

transition back to the community. CMS should also encourage states to enact more expansive allowances for home maintenance beyond the federal minimum.

- CMS should prioritize full implementation of the HCBS Settings Rule, ensure states provide robust enrollee protections, and maintain strong ongoing enforcement. CMS should also work with states to expand integrated housing options so that individuals residing in settings that are determined unable to become compliant are not unhoused or forced into institutions.
- CMS and ACL should work together to ensure people needing LTSS receive culturally competent counseling about their options and the Medicaid application process. States should be required to routinely assess institutional residents' desire to receive LTSS in a community-based setting and identify each individual's barriers to accessing HCBS. HCBS needs assessments must be accessible to people with communications disabilities and limited English proficiency.
- CMS should build on its efforts to ensure that all public and HCBS enrollee-facing materials are accessible and culturally relevant. Efforts must include robust beneficiary testing and opportunities for enrollees to provide input into design and implementation processes.

## End Medicaid Estate Recovery

Federal law requires that state Medicaid programs attempt to recover costs from estates of deceased recipients. Unfortunately, estate claims often force heirs to sell a family home that otherwise would have been passed down. Because home ownership is one of the few ways to build generational wealth for lower-income families, the burdens of estate recovery fall disproportionately on economically oppressed families and communities of color. Moreover, because of this discriminatory policy, some older adults choose to forgo Medicaid LTSS they need and are entitled to out of fear of financially burdening their families. In short, [Medicaid estate recovery policy perpetuates poverty and inequality for minimal return](#).

- CMS should proactively work with states to limit estate recovery to the minimum required under current law, using California's approach as a model.
- Congress should pass the *Stop Unfair Medicaid Recoveries Act* to repeal the federal requirement that state Medicaid programs go after families and estates for repayment of Medicaid long-term care services. At a minimum, Congress should change the law to allow states to decide whether to pursue estate recovery.

## Eliminate the Bias Toward Institutional Care

### Medicaid

While significant progress has been made to increase the share of Medicaid funding spent on HCBS, 55% of Medicaid LTSS expenditures continue to go to nursing facilities for older adults and people with physical disabilities. Both Congress and the Administration can take action to end the institutional bias and equitably increase access to HCBS in Medicaid.

- Congress should make HCBS a required Medicaid benefit available throughout every state without any arbitrary limits on enrollment. Justice in Aging supports introduction and passage of the *HCBS Access Act*.
- HHS should work across divisions to ensure [equitable access to currently available HCBS waiver services](#) through state and federal oversight that includes interventions to stop and prevent discrimination based on age, race, ethnicity, primary language, sex, sexual orientation, gender identity or other demographic factors.
- CMS should encourage states to take up the [State Flexibilities to Determine Financial Eligibility for Individuals in Need of Home and Community-Based Services](#) and, in doing so, consider ways to target options to enhance HCBS access for marginalized populations.

## Medicare

Because Medicare is nearly universal for people age 65 and older, it is important that it provide primary coverage of basic LTSS at home and not contribute to unnecessary institutionalization. This starts with taking immediate policy action to ensure that people with Medicare have access to home-based care that is at least equal to skilled nursing facility access.

- Congress must eliminate Medicare’s “home bound” definition for home health care. In the meantime, CMS should extend the expanded definition being utilized in the public health emergency and leverage demonstration authority to further expand its interpretation.
- CMS should evaluate the current Medicare payment system to ensure home health providers are offering and providing all services Medicare currently authorizes.
- CMS must enforce the *Jimmo* settlement so that nursing facilities and home health providers are using the proper standard for skilled nursing and therapy services under Medicare.
- CMS should remove the “in the home” restriction for durable medical equipment that prevents people with Medicare from accessing the equipment they need to participate in the community.
- Congress and CMS should make supplemental Medicare benefits equally available to those in fee-for-service as in Medicare Advantage to ensure all Medicare enrollees have access to the range of services they need to live independently.
- Congress and CMS should leverage lessons learned from models that expand access to HCBS for those dually enrolled in Medicare and Medicaid including, for example, the Program for All Inclusive Care for the Elderly and the Financial Alignment Initiative.
- Congress and CMS should evaluate telehealth expansions under the public health emergency and maintain flexibilities that increase and strengthen equitable access and prevent institutionalization.
- HHS should review Medicare program rules and use its civil rights enforcement authority to ensure that Medicare plans and providers are complying with the integration mandate under Section 504 of the Rehabilitation Act and the Americans with Disabilities Act.

Visit [Justice in Aging’s website](#) for more HCBS and LTSS resources. For a full summary of Justice in Aging’s health care priorities, see [Health Policy Priorities for the Biden Administration and New Congress](#).