The Better Care Better Jobs Act and Home- and Community-Based Services

Joe Caldwell

CLPC
Community Living Policy Center

Brandeis
THE HELLER SCHOOL FOR SOCIAL POLICY AND MANAGEMENT
Lurie Institute for Disability Policy

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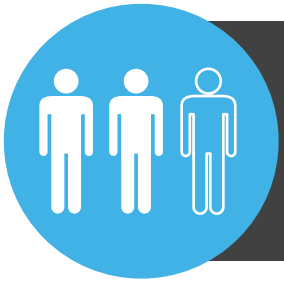
Introduction

The Biden–Harris administration has proposed a $400 billion investment in Medicaid Home- and Community-Based Services, or HCBS, which would allow more people with disabilities and older adults to receive services at home—and strengthen the direct-care workforce by increasing wages, benefits, and training opportunities.[1] This investment builds on the roughly $12.7 billion in dedicated funding for HCBS provided through the American Rescue Plan, which was enacted in March 2021. The Better Care Better Jobs Act (S.2210/H.R.4131) led by Senator Casey (D-PA) and Representative Dingell (D-MI-12) provides a foundation for realizing this historic investment. In this brief, we will highlight why people with disabilities and older adults need HCBS—and how the Better Care Better Jobs Act will help people stay in the community and out of nursing homes and other institutions.

Why should we invest more in HCBS?

Over the past several decades, states have shifted their Long-Term Services and Supports (LTSS) systems away from nursing homes and institutions—and toward HCBS. In 2018, Medicaid spent over half (56%) its funds for long-term services and supports on HCBS.[2] Despite this move toward HCBS funding, coverage remains uneven. For example, about 90% of total LTSS expenditures for people with intellectual and developmental disabilities, or IDD, are devoted to home- and community-based services. But ten states—including Illinois, Texas, and Mississippi—spend less than 75% on HCBS. Illinois and Texas spend only 54%, and Mississippi spends even less—33%. For older adults and people with disabilities other than IDD, the national average is only about 50%, and 12 states spend less than a quarter of their LTSS funding on home- and community-based services.

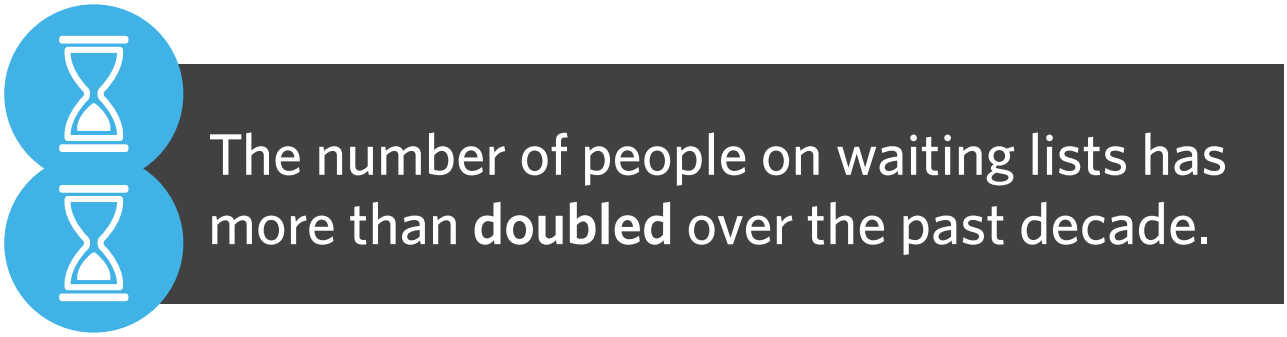


Two-thirds of people on HCBS waiting lists have intellectual and developmental disabilities.

States also report that more than 820,000 people—two-thirds of whom have intellectual and developmental disabilities—are on waiting lists for 1915(c) HCBS waiver programs.[3]

NOTE 1915(c) is the most common authority states have used to provide HCBS.

The number of people on waiting lists has more than doubled over the past decade. Although the average waiting time is just over three years, many people and families wait decades, receiving services only when crises arise. Waiting-list data undercount the true number of individuals and families who need, but have not yet received, HCBS. Not all states maintain waiting lists. National surveys have not included information about needs for long-term services and supports and whether people receive them.[4] We do know, however, that members of racial and ethnic minorities are less likely to have access to HCBS.[5, 6, 7]



Without qualified direct-care workers, people with disabilities and older adults cannot receive services and supports at home. Unfortunately, direct-care workers themselves face economic and social marginalization. The workforce consists primarily of women of color. Home-care workers are 87% female, and 62% are people of color.[8] The median hourly wage is $11.52, which translates into an annual salary of $16,200. Over half of workers (53%) rely on some form of public assistance.

People with disabilities, families, and providers often struggle to hire direct-care workers, since wages are typically low. This struggle has only increased over the past several years: more and more people need HCBS, and, because of demographic changes, fewer unpaid caregivers are available to help.[9] Low wages and benefits also contribute to high turnover rates among workers. Studies have found that the average annual turnover rate of home-care workers ranges from about 40% to 60%.[10, 11] Short-staffed, high-turnover agencies cannot provide enough care to everyone who needs it.

When people with disabilities and older adults do not receive support at home, they are often forced into costly nursing homes. But increases in HCBS, combined with rebalancing

efforts, allow states to better contain spending for long-term services and supports—and reduce overall costs.[12] Without home- and community-based services, people may use the emergency room or hospital more frequently, have worse health outcomes, and be isolated from their friends, family, and communities. Unpaid family caregivers, too, are shortchanged by the lack of HCBS: many have had to reduce their hours at work or quit their jobs altogether so that they could support their relatives.[13]

Major provisions of the Better Care Better Jobs Act

HCBS Infrastructure Improvement Program

The centerpiece of the proposed legislation is the HCBS Infrastructure Improvement Program, which provides states with additional federal funding to achieve two main goals: (1) Improve Access to HCBS; and (2) Strengthen and Expand the Direct-Care Workforce.

First, states will receive funding to develop plans for expanding the direct-care workforce and providing more people with home- and community-based services. Service recipients, family caregivers, advocates, direct-care workers, and other interested parties must be involved in developing states' plans. States are required to seek contributions from community members through formal notices and public-comment periods. Second, states must assess their HCBS programs' performance and identify ways to make them more equitable. Finally, they must develop detailed plans based on the following criteria:

Strengthen and expand access to HCBS:

- Address barriers and disparities in access and use of HCBS
- Expand financial eligibility criteria for HCBS up to federal limits
- Cover personal care services
- Adopt "no wrong door" enrollment systems, use of presumptive eligibility, and improve outreach and education efforts
- Expand access to behavioral health services and coordination with employment, housing, and transportation supports
- Expand supports for family caregivers, including respite
- Develop or improve programs to allow working people with disabilities to access HCBS (i.e. Medicaid Buy-In Programs)

Strengthen and expand the HCBS workforce:

- Ensure that payment rates for HCBS are sufficient to ensure access (i.e. improve direct-care workforce recruitment and retention)
- Update HCBS payment rates every two years through a transparent process with input from service recipients, family caregivers, direct-care staff, and other interested parties
- Ensure increases in HCBS rates are passed through to workers to improve compensation for direct-care workers
- Ensure rates are incorporated into managed-care arrangements
- Update, develop, and adopt qualification standards and training opportunities for direct-care workers and family caregivers
- Plans must specify activities and identify clear benchmarks. States submit plans to the Centers for Medicare and Medicaid (CMS) for approval.

Additional federal funding

After CMS approves their plans, states receive additional federal funding for implementation. Specifically, this includes:

- A continued 10% enhanced federal match for all their Medicaid HCBS spending.
- Increased federal reimbursement for associated administrative cost to 80%.[14] Currently these costs are reimbursed at 50%.

Quality, reporting, and oversight

In addition to enacting their plans, states are required to:

- Adopt a core set of quality measures for HCBS, or an alternative set approved by the Secretary.
- Designate an HCBS ombudsman office that would operate independently, provide direct assistance to beneficiaries and their families, and identify and report systemic issues.
- Annually report on elements of their HCBS improvement plan, activities, and progress in meeting benchmarks.

After seven years, in order to continue receiving the additional federal funding, states must be able to demonstrate the following:

- Increased availability of HCBS
- Increased utilization and availability of HCBS by populations with the lowest access
- Evidence that a majority of direct care workers receive competitive wages and benefits
- Rebalancing benchmarks[15]

States that do not meet these benchmarks at seven years would no longer be eligible for the enhanced federal funding. Also, states are prohibited from reducing HCBS benefits or making eligibility more restrictive during this time.

Additional enhanced funding for self-direction

States are also eligible to receive an additional 2% federal match for HCBS spending for one year if they establish programs that offer self-direction and meet the following criteria:

- Develop registries that connect beneficiaries with qualified workers
- Recruit independent providers and train them and beneficiaries
- Ensure safety and quality of care
- Facilitate communication and coordination between the state and HCBS direct-care workers
- Support beneficiary hiring of independent providers of HCBS (i.e. processing tax information, time sheets, claims, and payments)
- Where applicable, support beneficiaries who wish to hire family members and individuals with whom they have existing relationships
- Ensure that program policies and procedures allow for cooperation with labor organizations where applicable in states and that programs remain neutral with regard to organizing

Quality measurement and improvement

In the first two years of the legislation, the Centers for Medicare and Medicaid (CMS) must develop a core set and supplemental set of HCBS quality measures. The set will be reviewed

and updated annually. CMS must collaborate with other federal agencies and ensure that beneficiaries and their supporters help them develop and review their measures.

The core and supplemental set of HCBS measures must reflect the full array of HCBS services and beneficiaries and at a minimum include:

- Outcome-based measures
- Measures of the availability of services
- Measures of provider capacity and availability
- Measures of person-centered supports and services
- Self-direction measures
- Measures of transitions to and from institutions
- Surveys of beneficiaries and family caregivers

To assess equity, measures must provide data that allow for disaggregation by disability status, age, income, gender, race, ethnicity, geography, primary language, sexual orientation, gender identity, and type of service setting.

After CMS completes the core and supplemental set of measures, states are required to report annually on the measures for the first two years. As previously noted, states will receive an enhanced administrative match that will help strengthen their HCBS quality infrastructure.

Additional Provisions

Make the Money Follows the Person Program permanent

The Better Care Better Jobs Act makes the Money Follows the Person demonstration permanent. This long-standing program helps states rebalance their LTSS systems and move people out of nursing homes and other institutions back to the community. Evaluations have shown that the program saves states money and improves the quality of life for those who move back to the community from congregate housing.[16,17] The protections are currently set to expire in about three years. Making the program permanent will provide greater certainty to states and allow them to coordinate their Money Follows the Person programs with their HCBS Infrastructure Improvement plans.

Make the HCBS Spousal Impoverishment Protections permanent

The Better Care Better Jobs Act makes Spousal Impoverishment Protections permanent. These protections allow people with high support needs to qualify for Medicaid HCBS without requiring their spouses to forfeit all their income and assets.18 Although similar protections for people in nursing homes are permanent, the HCBS protections will expire in about three years. Extending these protections to people living in the community will prevent unnecessary institutional placements. Thanks to these protections, married couples will be able to stay together, and spouses will be able to afford to age in the community.

HCBS flexibilities during the COVID-19 pandemic

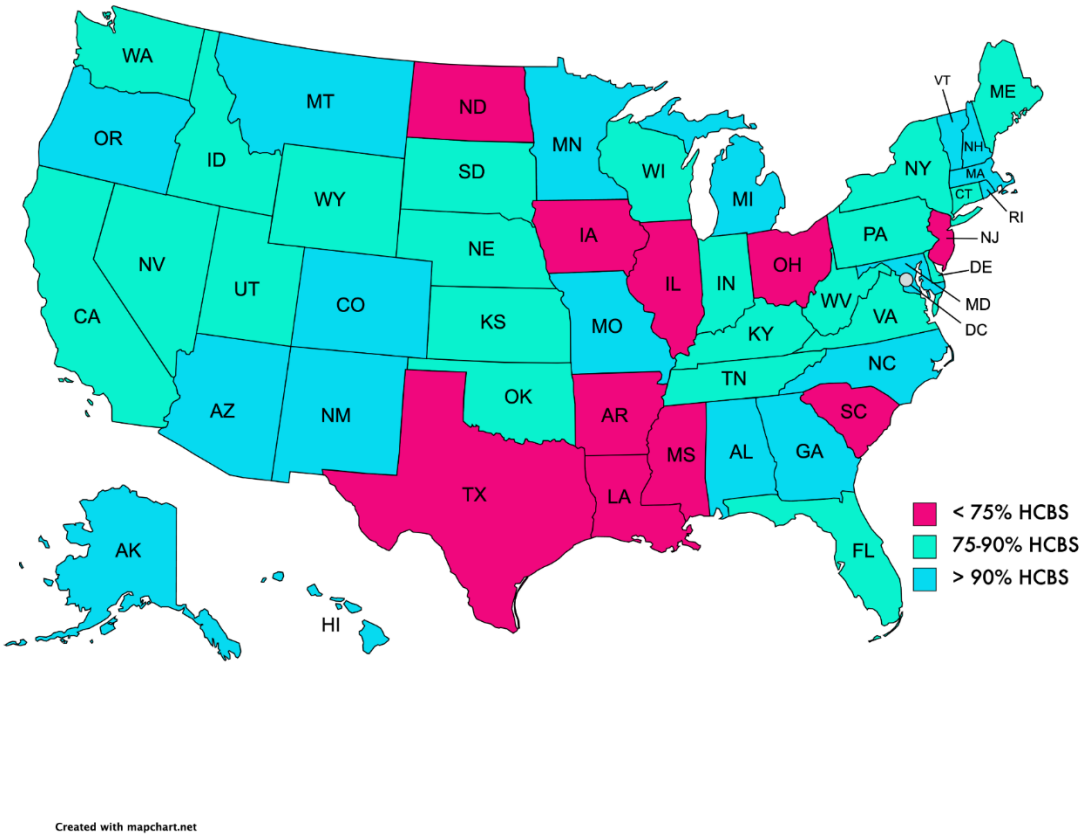
During the COVID-19 pandemic, states have had a great deal of flexibility to modify aspects of their Medicaid programs. Many states used a process known as Appendix K approval to modify their HCBS waiver programs.[19] For example, states modified eligibility, covered services, service planning and delivery, settings, provider qualifications and rates, oversight, and cost-sharing. Some of these changes may be beneficial to keep for the long term. Others, however, may weaken protections for beneficiaries. The Better Care Better Jobs Act instructs the Medicaid and CHIP Payment and Access Commission to conduct a study and provide recommendations to Congress.

Effects on older adults and people with disabilities, family caregivers, and the workforce

Over 3.5 million people currently receive Medicaid HCBS. The Better Care Better Jobs Act would help more people receive HCBS, strengthen the direct-care workforce, and improve HCBS quality and infrastructure. States will be able to transform their LTSS systems—and save money—by delaying or preventing placements in nursing homes and other institutions. An independent economic analysis of the Better Care Better Jobs Act estimated that the legislation would expand access to an additional 3.2 million older adults and people with disabilities, allow 1.1 million unpaid caregivers to return to the workforce, and create more than 500,000 new jobs for direct-care workers.[9]

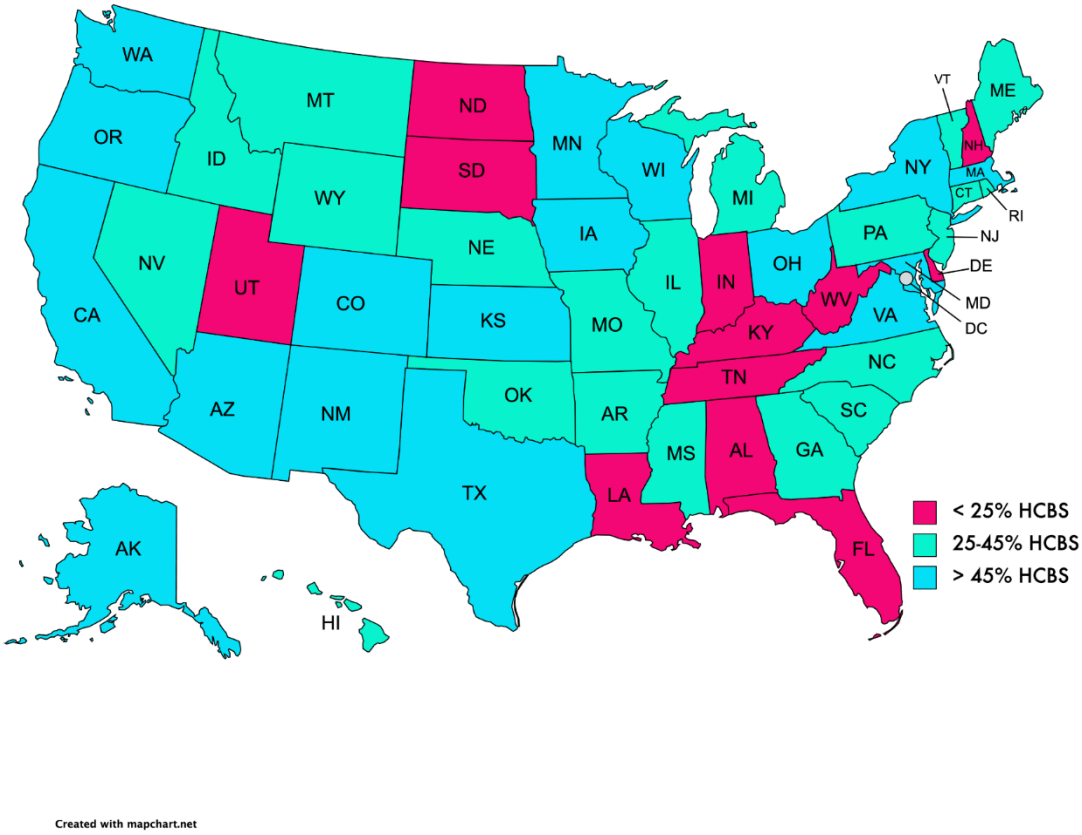
Appendices

Figure 1. Proportion of Medicaid LTSS Spending on HCBS for People with Intellectual and Developmental Disabilities



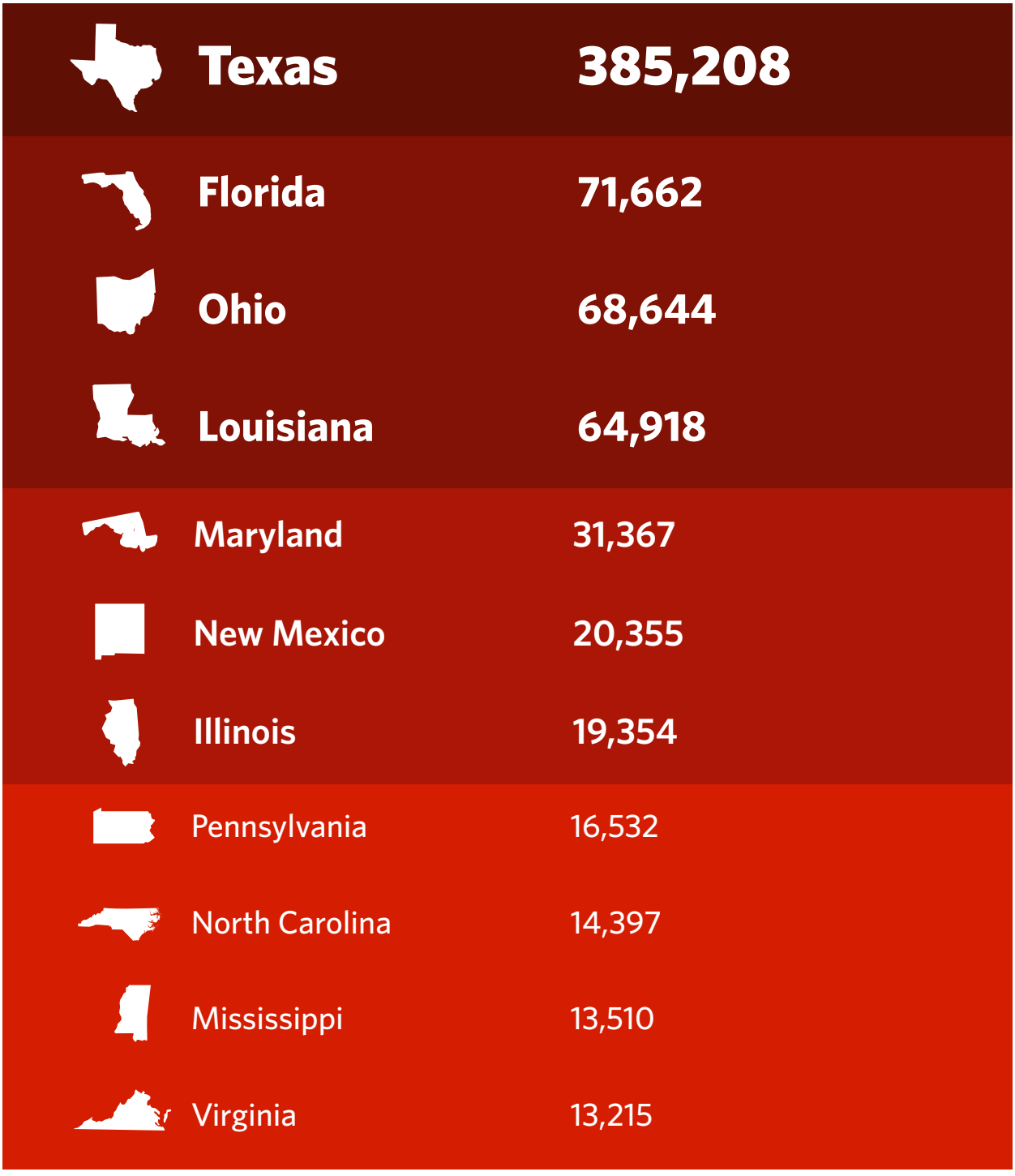
Source: Data from CMS/Mathematica with adjustments by H. Stephen Kaye, Community Living Policy Center[22]

Figure 2. Proportion of Medicaid LTSS Spending on HCBS for Older Adults and People with Disabilities Other than IDD



Source: Data from CMS/Mathematica with adjustments by H. Stephen Kaye, Community Living Policy Center[23]

States with Highest Number of People on HCBS Waiting Lists



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14. Administrative costs include costs for Medicaid data and technology infrastructure, modifying rate setting processes, adopting, using, and reporting quality measures and beneficiary and family caregiver experience surveys, adopting or improving training programs for direct-care workers, and adopting, carrying out, or enhancing programs that register qualified direct-care workers or connect beneficiaries to qualified direct-care workers.

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How to Cite This Brief

Caldwell, J. (2021). Better Care Better Jobs Act: Historic Investment to Improve Access to Home and Community Based Services and Strengthen the Workforce.

Community Living Policy Center. Brandeis University, Waltham, MA.

Contact Us

Web: communitylivingpolicy.org

Twitter: @CLPolicy

Funding Statement/Disclaimer

The Community Living Policy Center (CLPC) is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research, grant number 90TRCP0004. NIDILRR is a Center within the Administration for Community Living (ACL), U.S. Department of Health and Human Services (HHS). This website's contents reflect the views of the authors and not the National Institute on Disability, Independent Living, and Rehabilitation Research.