

BACKGROUND

Long Term Supports and Services (LTSS) provide individuals with disabilities and older adults with assistance with daily tasks, such as bathing, getting dressed, feeding oneself, and getting out of bed. It can also include assistance with broader tasks such as managing medications, housekeeping, and transportation. LTSS is not covered by commercial health insurance or Medicare. The federal/state Medicaid program is the major – often only – source of funding for LTSS that many people with intellectual and developmental disabilities (IDD) rely on to live in the community.

Home and Community-Based Services (HCBS). The term LTSS includes both facility-based services and home and community-based services (HCBS). HCBS helps people with IDD live independently in the community rather than in institutions. Unfortunately, the Medicaid program mandates nursing home coverage and makes HCBS optional.

ISSUES

Direct Care Workforce Crisis. Inadequate Medicaid payments have resulted in low wages for direct care workers who provide HCBS. Low wages mean that HCBS providers cannot attract enough direct care workers and related support staff. According to one government study, direct care worker wages were on average \$3.15 lower than wages in other entry level jobs.

HCBS Waiting Lists. Because HCBS is optional under the Medicaid program, over 690,000 people are on waitlists for HCBS. This means some individuals are unnecessarily institutionalized and many rely on unpaid family supports. As a result, parents and other family members often leave the workforce to provide support, causing enormous economic distress to these families.

End of COVID-19 Funding. In March 2020, Congress provided a temporary increase in the federal Medicaid match rate so long as states provided “continuous coverage” in their Medicaid programs. That increase completely expired at the end of 2023. Additionally, the American Rescue Plan Act provided funds specifically for HCBS. States have been allocated those funds and have until March 2025 to spend them. Unfortunately, many states are now reporting budget deficits and some are cutting back access to HCBS.

WHAT SHOULD CONGRESS DO?

The HCBS Relief Act (S. 3118/H.R. 6296). Under this proposal, states would receive a two year, 10-point increase in the federal match (FMAP) for Medicaid HCBS. States could use these funds to increase direct care worker pay, provide better benefits, support family caregivers, and reduce waitlists.

The HCBS Access Act (S. 762/H.R. 1493). Medicaid mandates only nursing home coverage while HCBS is optional. Far too many people remain trapped in institutions or are reliant on unpaid caregivers to stay at home. The HCBS Access Act would make HCBS coverage mandatory in Medicaid and end the institutional bias for good.

The Better Care Better Jobs Act (S. 100/H.R. 547) would invest over \$300 billion in the HCBS system, reducing waiting lists and increasing wages for direct care workers. Significant investments are needed to preserve and expand access to services and address the crisis in the workforce. The workforce crisis, including low wages and increased turnover, is worse than ever and people cannot access supports due to the shortages. In many states, insufficient state Medicaid reimbursement rates do not allow for an adequate response to these urgent needs, making major federal investments even more critical.

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FOR MORE INFORMATION PLEASE CONTACT

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