



## **2024 Legislative Priorities for the CCD Long Term Supports and Services Task Force**

The [LTSS Task Force](#) addresses the services and supports that enable individuals with disabilities of all ages to live in their own homes and communities, known as Home and Community-Based Services (HCBS). HCBS, which are primarily provided through Medicaid, are necessary for the community integration, full participation, independent living, and economic self-sufficiency for many people with disabilities and older adults and makes it possible for them to fully exercise their civil and human rights.

The CCD LTSS TF considers the equity impact of any legislative proposal we support, and incorporates anti-racism into all our work, in accordance with the LTSS Task Force's anti-racism principles and objectives.

The following is a non-exhaustive list of the Task Force's legislative priorities. The Task Force will also support other legislative action that furthers the task force's priorities or mission statement, on a case by case basis.

### **1) Expand Home and Community Based Services and Address the Medicaid Institutional Bias**

Medicaid currently has an institutional bias -- institutional services like nursing facilities are mandatory and home and community based services (HCBS) are optional. As a result, people with disabilities and older adults who prefer to receive services in their own homes and communities often must wait on years-long waitlists for HCBS, while others live in states where the services they need are simply not offered. Even more individuals receive inadequate levels of services. The LTSS Task Force supports the following proposals to expand access to HCBS.

- **Extend Money Follows the Person and Spousal Impoverishment Protections:** Medicaid [Money Follows the Person](#) (MFP) allows states to rebalance more funds towards HCBS. This program enables people with disabilities to transition from institutions to community settings. Meanwhile, spousal impoverishment protections allow the spouse of an HCBS enrollee to retain some income and resources to pay for their essential needs while their spouse receives long-term care. These protections are guaranteed

for individuals whose spouse is receiving care in an institution. However, funding for MFP and spousal impoverishment protections when the spouse receives HCBS is limited, with the current funding set to expire in 2027. The Task Force will work to extend the funding beyond 2027, and preferably provide permanent funding for these programs.

- Provide Immediate Relief by Passing the HCBS Relief Act: The [HCBS Relief Act](#) would provide states a 10% increase in the federal matching rate for Medicaid funded HCBS for two years. These funds could help states raise wages and benefits for direct care workers, address waiting lists, expand the workforce, and otherwise provide immediate relief for individuals who depend on HCBS.
- Expand and Strengthen HCBS: The [Better Care Better Jobs Act](#) would provide a much needed investment in HCBS, including investing in the direct care workforce by addressing insufficient payment rates and requiring that rate increases are passed on to direct care workers; increasing the availability of personal care services; expanding access to community-based behavioral health services; providing support to family caregivers; improving coordination of HCBS with housing, transportation, and employment supports; and would permanently reauthorize Money Follows the Person and HCBS spousal impoverishment protections.
- Make Home and Community Based Services (HCBS) a Mandatory Medicaid Benefit: The institutional bias could be addressed by making HCBS a mandatory Medicaid service under 1905(a), as is proposed in the [HCBS Access Act](#). A new, single, overarching HCBS authority would alleviate some of the complexity and administrative costs associated with the program, align financial eligibility pathways, and replace enrollment caps with functional eligibility criteria. A consolidated HCBS authority would also align, and could strengthen quality expectations, and would streamline reporting requirements for states, increasing data availability. Such efforts could be coupled with financial incentives to states to build capacity for community-based services, which would help address the workforce crisis and improve availability and quality of home and community based services.
- Provide Incentives for States to Provide Robust Community-Based Mental Health Services: Like other HCBS, intensive, community-based mental health services and supports are not mandatory. Individuals who rely on these supports often have to navigate a patchwork of poorly coordinated, under-resourced services. The LTSS Task Force supports legislation such as the [Strengthening Medicaid for Serious Mental Illness Act](#), which would create a tiered Federal Medical Assistance Percentage (FMAP) increase to incentivize states to provide intensive community-based services to individuals with “serious mental illness.” These services would

include services that have proven effective to support individuals with high support needs in the community.

## **2) Reduce Institutionalization of Youth with Disabilities**

All children, including children with disabilities, belong with families. The Family First Prevention Services Act (FFPSA) of 2018 contained certain protections to reduce the use of long-term congregate care facilities for children in foster care with significant behavioral health needs and support these children in the community. The LTSS Task Force opposes [proposals](#) that would make it easier for states to obtain reimbursement for congregate care facilities and long term institutions for such children.

## **3) Improve Data Collection, Analysis, and Public Reporting**

In order to improve quality and ensure equity, we need much more data on HCBS, including on both the people who use services and the people who provide them. Furthermore, there is scant data and understanding on how COVID-19 and the end of the public health emergency continues to impact people with disabilities who live in the community. This is especially problematic with regard to those who require HCBS, including those who receive HCBS outside of Medicaid. Data collected and analyzed should also include race, ethnicity, primary language, disability type, benefits status, and other demographic characteristics to ensure that these intersectional disparities are identified and addressed.

- Include in-depth data reporting requirements in legislative proposals that seek to improve HCBS, and invest in infrastructure necessary to support this data collection and analysis. This information should include race, ethnicity, disability status, age, sex, sex characteristics, sexual orientation, gender identity, primary language, rural/urban environment, and service setting, to ensure that these intersectional disparities are identified and addressed. The LTSS Task Force will continue to use the language developed by the Health Task Force and DAC to ensure comprehensive data collection, particularly as states undertake unwinding.
- Create a Standard Occupational Classification (SOC) for Direct Support Professionals (DSPs). DSPs provide supports that cover a wide range of habilitation services including, support and skill-building for activities of daily living, employment, transportation, and other supports that promote independence and community inclusion. Currently, “Direct Support Professional” is not recognized at the federal level because it does not have a unique SOC which contributes to inaccurate and inconsistent data collection. The bipartisan [Recognizing the Role of Direct Support Professionals Act](#) would require the Office of Management and Budget to consider the creation of a DSP SOC.

#### **4) Reduce the Use of Estate Recovery:**

The Task Force supports efforts to repeal or limit estate recovery, including the [Stop Unfair Medicaid Recoveries Act](#). Current federal law requires state Medicaid programs to seek repayment of Medicaid long-term care benefits, even if the state would prefer not to seek that recovery. States must seek recovery from the heirs of the deceased Medicaid recipient, preventing families from building generational wealth through homeownership, exacerbating existing economic inequities. These rules are especially detrimental to families of color that have lower homeownership rates because of discriminatory lending and housing policies, and the families of people with disabilities, who need months or years of long-term services and supports.

#### **5) Address the Direct Care Workforce Crisis**

Despite the ever-growing demand for direct care workers, this workforce is experiencing a severe workforce crisis with a national average turnover rate of 45 percent. Funded primarily by Medicaid, direct care workers suffer from low wages, high turnover, poor benefits, and limited pathways for advancement. Taken together, this leads to gaps in available services and supports. This is also a racial equity issue, as over half of the direct care workers are BIPOC individuals, the majority of whom are women of color. Turnover can be as high as 60 percent in some states. This has a profound impact on the quality of life of people with disabilities. All too often, Medicaid enrollees with LTSS needs are left with an entitlement to services.

To support the direct care workforce and the disability community, CMS and Congress must pursue policies to increase direct care worker wages and benefits, and explore innovative solutions for back-up services. In addition, enhanced administrative match funding should be made available to states and providers to support pipeline initiatives that will train, recruit, and retain the workforce and improve the likelihood of their beginning, success, continuation, and availability during personal or public emergencies. As noted above, we support the Better Care Better Jobs Act, the HCBS Relief Act, the HCBS Access Act, and other proposals that will strengthen and expand this workforce.

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**UPDATED February 2024**