



2023 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 Task Force federal legislative priorities include:

Commitment to Anti-Racism and Equity

CCD LTSS TF commits to considering the equity impact of any legislative proposal we support, and to incorporating anti-racism into all our work, in accordance with the LTSS anti-racism principles and objectives. As a task force, invite speakers and share readings to educate ourselves about white privilege and anti-racism. We also commit to discussing and considering the equity impact of major legislative or policy positions prior to taking a position as a task force. Data collection, analysis, and publicly transparent reporting is critical to monitoring and measuring access to HCBS. The CCD LTSS Task Force supports efforts to create a comprehensive, consistent, federal standard for demographic collection and ensure that states have the resources to necessary to meet the standard. The antiracism subcommittee meets regularly to review policy positions and priorities to ensure that racial equity is embedded in our work, and suggest additional priorities.

Expanding Home and Community Based Services and Addressing the Medicaid Institutional Bias

Making Home and Community Based Services (HCBS) a mandatory Medicaid benefit
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. This institutional bias could be

addressed by making HCBS a mandatory Medicaid service under 1905(a) like institutional care, as was proposed in the discussion draft of 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 Direct Support Professional workforce crisis and improve availability and quality of home and community based services.

Status: A discussion of draft of the HCBS Access Act was released in May 2021, and CCD LTSS submitted comments. LTSS intends to renege to advocate that the bill be introduced in the 118th Congress, and will work to build support for the bill.

Expand & Strengthen HCBS by Passing Better Care Better Jobs Act

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.

Status: Ongoing.

Protect Family First Prevention Services Act Provisions to Reduce Institutionalization of Youth in Disabilities in Foster Care

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. There have been proposals, including the “Ensuring Medicaid Continuity for Children in Foster Care Act of 2021” (S.2689) that would undermine the goals of FFPSA by making changes to Medicaid that would make it easier for states to obtain reimbursement for congregate care facilities and long term institutions for such children. We will oppose proposals such as the S. 2689 that undermine this basic premise.

Status: Ongoing.

Medicaid for Workers with Disabilities

Medicaid for Workers with Disabilities (“Medicaid Buy-In”) was authorized under the Balanced Budget Amendment of 1997 and the Ticket to Work and Work Incentives Improvement Act (TWWIA) in 1999. These programs offer individuals with disabilities the opportunity to work and access the healthcare services and supports they need, without having to choose between working and qualifying for Medicaid. Through the program, people with disabilities who are working can retain their healthcare coverage through Medicaid, while earning more than the allowable limits for regular Medicaid. Individuals in the program pay a premium to Medicaid in order to participate; the premium amount varies by state. As of 2022, all but three states operated a Medicaid buy-in program. However, there is considerable variation between state buy-in programs, and individuals participating in a buy-in must reapply if they move between states. We would like to work on creating national standards to improve the utility and adoption of the Medicaid Buy-In programs, and promote funding for additional education and outreach about the program.

In addition, the Medicaid Buy-In under TWWIA is limited to those between the ages of 16-64 years of age. Once an individual turns 65 they are no longer able to participate and are required to stop working in order to maintain their Medicaid benefits. Individuals with disabilities over the age of 64 should be able to continue work and participate in the TWWIA Medicaid Buy-In program. There should be a statutory change to allow individuals with disabilities over the age of 65 to pursue employment opportunities and maintain their Medicaid benefits.

Status: Ongoing.

Inclusion of LTSS in Health Care Reform

There is extremely limited access to LTSS in private insurance or Medicare, and few families have the means to pay for these daily services on an ongoing basis, much less for the decades or lifetime that people with disabilities often need these services. This has left Medicaid as the main payer of LTSS. But Medicaid disadvantages HCBS because it has an “institutional bias” that mandates states to cover most institutional services while making coverage of HCBS optional. States can and do cap access to HCBS, creating waitlists or other restrictions to access, which the disability community strongly opposes. These waitlists and restrictions force many people with disabilities and older adults to rely on unpaid family caregivers and other programs that ensure access to housing, nutrition, work supports, and other basic needs, if available. Failure to provide retroactive coverage for HCBS beneficiaries while Medicaid retroactive coverage is available for institutional services exacerbates the institutional bias. Inability to access needed services and supports can also lead to job loss, unnecessary interactions with the criminal justice system, homelessness, or greatly diminished health and function. For those who can access services, Medicaid’s strict eligibility criteria trap people with disabilities and older adults in poverty to obtain services, hindering

the economic opportunities and ability to save for their families' future or for their own retirement. The state-federal partnership that underpins Medicaid also means that there is substantial state variation in access to LTSS and even greater variation in access to HCBS. The Affordable Care Act began to establish a federal floor of covered services, which includes mandated access to some of the critical services people with disabilities and older adults need including rehabilitation, habilitation, prescription drugs, and behavioral health services. However, these "essential health benefits" are not enough to meet the need for LTSS, and private health insurance can still discriminate against people with disabilities by covering services provided in institutions but not in community settings. LTSS TF will continue to advocate for improvements to all kinds of currently available insurance, and will also advocate that any universal health care proposals address the full range of services that are critical to people who need and use LTSS. A universal or "for all" health care system must establish and guarantee access to a standard benefit package that includes LTSS in all health insurance. Any new system must also preserve the decades of progress that provides protections for people with disabilities, including the Early and Periodic Screening, Diagnostic and Treatment mandate and other consumer protections.

Status: We will continue to work with legislative offices to ensure that major health care coverage reform proposals are comprehensive and address the needs of people who rely on LTSS.

Data collection, analysis, and public reporting

In order to improve quality and ensure equity, we need much more data on HCBS, including both the people who use services and the people who provide them. Furthermore, there is scant data and understanding on how COVID19 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 include race, ethnicity, primary language, disability type, benefits status, and other demographic characteristics to ensure that these intersectional disparities are identified and addressed. The LTSS Task Force supports the inclusion of in-depth data reporting requirements in policies that seek to improve HCBS, as well as investments in the 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.

Status: Ongoing.

Estate Recovery

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. The Medicaid program's claim is enforced against the heirs of the deceased Medicaid recipient. Medicaid estate claims prevent 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.

In 2022, the [Stop Unfair Medicaid Recoveries Act](#) (H.R. 6698) was introduced, which would prohibit states from purposing estate recovery. LTSS wrote a letter in support. LTSS will continue to support proposals to either prohibit estate recovery.

Status: New priority.

Direct Care Workforce

Address the Direct Care Workforce Crisis

The direct care workforce, and specifically the Direct Service Provider (DSP) workforce, is one of the fastest-growing professions in the U.S. due to demographic trends such as the increase in autism diagnoses and longer lifespan of people with disabilities. Despite the ever-growing demand for DSPs, 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.

Status: Some aspects of the above proposals have been included in the Better Care Better Jobs Act, and we will advocate that workforce provisions are included in HCBS Access Act.

Creation of a Standard Occupational Classification (SOC) for Direct Support Professionals (DSPs)

DSPs support millions of people with disabilities to help them live in the community. DSPs need a federal designation specific to their occupation to recognize the profession and inform policy-making. Currently, “Direct Support Professional” is not recognized as a profession at the federal level because the Bureau of Labor Statistics (BLS) has not given it a Standard Occupational Classification (SOC). Congressional action is needed to encourage BLS to create a SOC for DSPs because:

- The umbrella SOC that BLS categorizes DSPs under does not accurately reflect the profession. BLS mixes DSPs into an umbrella category that includes home health aides, social workers and camp counselors. While there is some overlap between DSP duties and those professions, DSPs have much higher levels of responsibility not reflected in current BLS descriptions.
- This is problematic because SOCs are heavily used to inform policy-making. SOCs are used to help all levels of government (local, state, federal) identify employment trends and design policies including: state rate setting for Medicaid supports, investment decisions by Workforce Investment Bureaus, and targeted recruitment programs. The current classification does not reflect the true nature of DSP work, preventing policy-makers from making the most informed decisions in these areas.
- Creating a SOC would not cost the federal government anything. BLS already collects data from I/DD agencies which employ DSPs, so this would not be a question of creating a new data collection system – it would simply be adding the DSP data in the data set.

In addition, the current definition of Personal Care Attendant in that SOC does not appropriately indicate that some PCAs provide services that are medical in nature. The SOC definition for Personal Care Attendants should be revised to reflect that PCAs may provide medical assistance.

While the proposed SOC for DSP defines DSPs broadly and does not limit the classification to direct support workers for individuals with intellectual and/or developmental disabilities, the LTSS Task Force supports other initiatives to recognize, support, and expand the work of all direct care workers that support individuals with disabilities, including but not limited to behavioral health peer support workers, community support workers, and community health workers.

Status: House and Senate bills directing BLS to create a DSP SOC using the definition of a DSP in the HIIA were introduced in the 117th Congress, and will be reintroduced in the 118th Congress. We will continue to advocate for its passage.

Technology

Medicaid Directors Letter Encouraging Use of Technology in HCBS

Emerging and innovative technology not only can be one of the solutions to the DSP workforce crisis, but can also help to support individuals with greater privacy and independence in their home and allow reinvestment of cost savings into priorities like waiting lists for services. However, CMS has not provided states or providers serving people with disabilities with clear, consistent policy guidelines regarding Medicaid reimbursement for technology driven services. In particular, CMS operation of Medicaid reimbursement rules regarding software applications (e.g. phone apps), tablet technology (e.g. iPads), smart home technology, and maintenance of technology solutions has not evolved as the societal role of these technologies has changed. We seek explicit guidance from CMS to confirm Medicaid payments are authorized for the use of innovative technology solutions to deliver HCBS waiver services.

Status: Ongoing. We are currently meeting with offices about legislation that would direct CMS to clarify that states can receive Medicaid reimbursement for technology for enrollees' benefit that improves or maintains functioning and independence, and to specifically clarify that Medicaid funds are available for purchase, upkeep and repair of augmentative and alternative communication software and devices that have multiple uses.

Technology Infrastructure, Adoption, and Training Grants for States and Providers

Improving and maximizing the effectiveness of technology will be key to addressing the challenges facing Medicaid LTSS in the 21st century. As the need for effective quality measures in HCBS and the data collection to support them becomes increasingly more pressing, so does the need for IT infrastructure to support these efforts. Through the Transformed Medicaid Statistical Information System (T-MSIS) and several other initiatives, significant effort and investment has gone into improving state IT systems; however, the IT systems used by providers, which must feed into those state systems, have received less attention. Technology can also be used to address the DSP workforce crisis, both through tools that make basic DSP administrative functions more efficient, and through technology that can help meet the service needs of HCBS recipients. Of course, in order to maximize the impact of this technology, providers and their employees must be sufficiently trained in its use. The effort to modernize Medicaid will require more concentrated effort than is supported by administrative claiming. Therefore, we propose a Medicaid Modernization Grant Program through which states can receive grants specifically for developing provider capacity to use technology, in three buckets: 1. building quality reporting infrastructure to feed into the state's

data IT systems; 2. purchasing technology that can be used either to modernize employee practices or to improve direct services; and 3. training people on the use of said technology. Funding for training could also be built into awards in the first two buckets, rather than being a separate track. Funding to address this priority could also be folded into a HCBS Infrastructure proposal.

Status: Preliminary meetings ongoing.

Other

Address impact of climate change and environmental disasters on LTSS

Hurricanes, wildfires, floods and other natural disasters occur at an increased rate across the country, causing individuals to migrate both on a temporary and permanent basis. However, individuals who rely on LTSS face specific challenges. LTSS is primarily provided via Medicaid, and relocating to a new state may force an enrollee to languish years on the new state's wait list for services, if such services are even available. Even for moves within a state, locating new providers and support quickly is a difficult challenge. The task force will continue to support approaches such as those in the Disaster Relief Medicaid Act, that seek to create national solutions to ensure those who receive LTSS can relocate safely in response to such disasters.

Status: Ongoing. LTSS will continue to work with the Emergency Management Task Force to support efforts.

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