



**CONSORTIUM FOR CITIZENS
WITH DISABILITIES**

**2021 Legislative Policy Proposals for Improving Medicaid
Home and Community Based Services from the
Long Term Supports and Services Task Force**

**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. This option was included in a [CBO Healthcare Options paper](#) in 2008. 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. This concept has been developed further in [a white paper from the Kaiser Family Foundation](#). 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: Ongoing conversations with interested parties.

**Expanding & Strengthening HCBS Infrastructure by passing the HCBS Infrastructure
Investment Act**

HCBS Infrastructure Investment Act text was introduced in the Senate and was set to be introduced on a bipartisan basis in the House but was delayed due to COVID19. Priorities for a new program include funding to assist states with implementing the HCBS Settings Rule, expanding employment opportunities, transportation, workforce development, employment for people with disabilities, case management and assistance with community housing, and

funding to address necessary changes in the way HCBS is delivered to address COVID-19 risk. The bill also includes a focus on quality measures for HCBS.

Status: We will work for bipartisan bills in both the Senate and House in the next Congress.

Permanent Reauthorization of Money Follows the Person and HCBS Spousal Impoverishment Protections

A permanent reauthorization of the Money Follows the Person program continues to be a top priority of the disability and aging communities, especially as multiple short-term reauthorizations have led to a precipitous decrease in transitions and multiple states dismantling their programs without the assurance of reliable funding. Permanent reauthorization should also include provisions to ensure equitable access, particularly for BIPOC. Permanently incorporating elements of the MFP program into Medicaid HCBS authorities could be enhanced by expanding on MFP's role in rental assistance by allowing short term "bridge" rental assistance beyond the first month in order to facilitate connection to other rental assistance programs¹. The disability community has also been working together with the aging community on reauthorization of the HCBS Spousal Impoverishment Protections, which has been paired together with MFP through repeated short-term extensions.

Status: Short-term reauthorization of MFP and Spousal Impoverishment Protections through December 11, 2020. While another short-term extension is possible, we will be advocating for permanent reauthorization of both programs.

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 2015, 44 states operate a Medicaid buy-in program; six states, AL FL, HI, MO, OK, and SC do not offer the program. In 2011, nearly 200,000 individuals were enrolled in the 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.

¹<https://www.medicaid.gov/medicaid/long-term-services-supports/downloads/mfp-2019-transitions-brief.pdf&sa=D&ust=1601914681169000&usg=AFQjCNFxe2wc89JGz8o2o1pg0sMR41CYMA>;
<https://heller.brandeis.edu/community-living-policy/images/pdfpublications/2020maymfpbrief.pdf>

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: Senate and House bipartisan bills introduced to address the 65 and over barrier (HR 5429 and S. 3010). We also met with offices that have proposed a Medicaid-based public option, to advocate for expanded access to HCBS in such programs.

DSP Workforce

Pipeline Programs for Direct Service Providers (DSPs)

The disability community has a workforce crisis, specifically for the direct service provider (DSP) workforce. Funded primarily by Medicaid, the 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. 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.

To support the DSP workforce and the disability community, CMS and Congress must pursue policies to increase DSP 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 DSP workforce and improve the likelihood of their beginning, success, continuation, and availability during personal or public emergencies.

Status: Some aspects included as part of the DIRECT CARE Act. Ensured workforce was included as a priority in the HCBS Infrastructure Investment Act. Meeting with other offices on other pipeline programs.

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 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.

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 116th Congress, and we will be working on reintroduction in the next year.

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 in their home and allow reinvestment of cost savings into priorities like waiting lists for services. However, providers serving people with disabilities have not received clear authority from CMS that they can be reimbursed for technology driven services, such as software applications (e.g. phone apps), tablet technology (e.g. iPads), smart home technology, or maintenance of technology solutions. 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: We are currently meeting with offices about legislation that would direct CMS to issue three separate Medicaid Directors letters on each of the following – use of technology in HCBS, use of telehealth in HCBS, and use of augmentative communication devices.

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: Have held meetings but not much progress yet.

Electronic Visit Verification (EVV)

Poor implementation of EVV continues across the country. Stakeholders agree that CMS and/or Congress must address biometrics, GPS, dual verification systems, host homes, family caregiving, etc. States risk losing up to 1% of the state federal medical assistance percentage (FMAP) as a penalty if they do not comply with EVV, which would be particularly ill-timed as HCBS providers struggle during COVID-19.

Status: The task force is seeking a legislative delay of EVV-related penalties and is advocating for guidance that would allow CMS to exercise discretion in assessing penalties.

COVID-19

Expand Funding for Home and Community-Based Services to Address COVID-19

Enhanced federal Medicaid reimbursement rates for home and community-based services for people with disabilities and older adults are crucial to safety during the pandemic. These provisions are key to expand the availability of these services that enable people with disabilities and older adults to stay safe in their own homes and communities and out of institutions and to transition out of institutions back to the community. In addition to concerns about overreliance on institutional settings in violation of the Americans with Disabilities Act and the Supreme Court's *Olmstead* decision, the pandemic has ravaged institutional settings,

jeopardizing the health and lives of millions of people with disabilities and older adults. Without reducing the census of these facilities, it is virtually impossible to implement adequate safety measures.

Expanding home and community-based services is a crucial step needed to address these concerns. Ensuring that community service providers have sufficient PPE, telehealth equipment and training are also critical, as is ensuring that housing subsidies are allocated for people with disabilities transitioning out of or diverted from institutions. In addition to the specific enhanced rates for home and community-based services. We support an enhanced rate for HCBS, an additional general FMAP bump for all Medicaid services, and continuing maintenance of effort (MOE) protections such as those included in the Families First Act. *Status:* The HEROES Act, passed by the House, contained a 10% FMAP bump for HCBS and a 14% general Medicaid FMAP bump. Legislation is not moving in the Senate. We will continue to advocate for these supports in the next year.

Data collection analysis and public reporting

We need to understand and respond to the way that COVID-19 is disproportionately impacting people with disabilities and older adults, particularly Black, Latinx, Indigenous and other people of color. Therefore, it is crucial that legislation require disability status data collection and reporting. Furthermore, certain settings where people with disabilities live, such as ICF-IDs and psychiatric hospitals, have been neglected when addressing the COVID-19 crisis. Therefore, it is tremendously important that the legislation require data collection and reporting of numbers and rates of COVID-19 testing, numbers and rates of hospitalizations, numbers and rates of intensive care admissions, and numbers and rates of deaths associated with COVID 19 in the following settings: nursing homes, psychiatric hospitals, intermediate care facilities for individuals with intellectual and developmental disabilities, assisted living facilities, and other congregate facilities where people with disabilities live. This information should include race, ethnicity, primary language and other demographic characteristics to ensure that these intersectional disparities are identified and addressed.

Other

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. 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. A universal or "for all" health care system must continue this progress by establishing and guaranteeing 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: All major universal health care proposals that have been introduced now include home and community based services. We will continue to work with offices to ensure that the coverage is comprehensive, and that any new proposals address the needs of people who rely on LTSS.

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: New priority.

Anti-Racism

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.

CCD LTSS co-chairs:

Alison Barkoff, Center for Public Representation (202-854-1270, abarkoff@cpr-us.org)

Julia Bascom, Autistic Self Advocacy Network (202-558-1270, ibascom@autisticadvocacy.org)

Dan Berland, National Association of State Directors of Developmental Disabilities Services
(703-683-4202, dberland@nasddds.org)

Nicole Jorwic, The Arc of the United States (630-915-8339, jorwic@thearc.org)

Jennifer Lav, National Health Law Program (202-552-5139, lav@healthlaw.org)

Sarah Meek, American Network of Community Options and Resources (ANCOR)
(703-535-7850 x104, smeek@ancor.org)

UPDATED OCTOBER 2020