

BACKGROUND

Long Term Services and Supports: The federal/state Medicaid program is the major – often *only* – source of funding for long term supports and services (LTSS) that many people with intellectual and developmental disabilities (IDD) rely on to live in the community. This effective and cost-efficient program is critical to people with IDD, making it possible for them to live and work among their neighbors. Congress and the Administration must strengthen and modernize the Medicaid program.

Home and Community-Based Services: LTSS is the term that includes both facility-based services and home and community-based services (HCBS). HCBS services include everything from assistance getting around the community, employment supports, and other services to assist with independence. Currently many states have long waiting lists for participation in Medicaid-funded community-based supports and services. As the population ages, the need for LTSS will increase for both people with IDD and their family caregivers. To meet these growing needs Medicaid should be strengthened, and other proposals should be developed, to expand access to LTSS inside and outside of the Medicaid program.

ISSUES

Expanding Access to HCBS: Shifting the LTSS system to ensure that anyone who needs HCBS has access without a wait is going to take a major investment. The push for more integrated community-based settings instead of more costly congregate institutional settings must be expanded. The COVID-19 pandemic has shown the public health danger of large congregate settings; the alternatives are HCBS. Additional investments and changes to the Medicaid law to remove existing institutional bias would allow investment in community services to grow. One program that has supported the rebalancing efforts of states is the Money Follows the Person (MFP) program. MFP incentivizes investment in HCBS by providing federal funding for transitional services for individuals who wish to leave a nursing home or other institution. While the program was reauthorized for an additional three years, funding has been allowed to expire and states need the program to be stable into the future. The American Rescue Plan provided a one year investment of \$10 billion in HCBS funding to respond to the

APRIL 2, 2021

FOR MORE INFORMATION PLEASE CONTACT

American Association on Intellectual and Developmental Disabilities at (202) 387-1968
Association of University Centers on Disabilities at (301) 588-8252 • Autism Society at (301) 657-0881
National Association of Councils on Developmental Disabilities at (202) 506-5813
National Down Syndrome Congress at (770) 604-9500 • Self Advocates Becoming Empowered at SABEnation@gmail.com
TASH at (202) 817-3264 • The Arc at (800) 433-5255 • United Cerebral Palsy at 800-872-5827

pandemic and address the critical life-threatening needs of people with IDD and the service delivery system that supports them. This funding is a critical short term solution but more needs to be done to support people with IDD in the recovery.

HCBS Settings Rule: The HCBS Settings Rule, released by the Centers for Medicare & Medicaid Services (CMS) in January 2014, requires that Medicaid-funded HCBS programs be faithful to the original intent of the program. This requires them to support settings that maximize opportunities to live, work, and receive services in integrated, community settings where people with disabilities and older adults can fully engage in community life. In so doing, the Rule defines minimum standards for residential and non-residential settings to be considered “home and community-based.” The purpose and impact of the Rule is to ensure that individuals receiving HCBS have full access to the benefits of community living; to enhance the quality and availability of HCBS; and to provide basic protections to participants.

Housing: Medicaid provides essential services and supports, but by law typically cannot pay for a person’s rent or mortgage payment. Programs operated by the Department of Housing and Urban Development (HUD) help make housing affordable (through rent subsidies) and help create new affordable, accessible housing. These include Section 811 Project Rental Assistance, Mainstream Vouchers and other Housing Choice Vouchers. Even with these programs, the need for affordable, accessible housing for people with disabilities is far greater than the availability.

WHAT SHOULD CONGRESS DO?

- Members of Congress should act to remove the institutional bias of federal programs, eliminate waiting lists for LTSS, and create a right to community living for individuals with disabilities.
- Congress must understand that Medicaid supports people with disabilities to live and work in their communities and Medicaid should be expanded.
- Congress should address the nation’s need for an affordable, accessible system of long term supports and services.
- Congress should make the Money Follows the Person Program permanent.
- In recovery, Congress must provide additional funding for HCBS services, the workforce that provides them, and for additional affordable, accessible, and integrated housing.