

BACKGROUND

Long Term Supports and Services: The federal/state Medicaid program is the major – sometimes the only – source of funding for long term supports and services (LTSS) that many people with intellectual and/or developmental disabilities (I/DD) rely on to live in the community. This program works and is cost effective. This program is critical to people with I/DD, making it possible for them to live and work among their neighbors. Proposals that cut or cap the Medicaid program, or provide block grants to states, hurt all people receiving Medicaid, but especially people with disabilities. This is because they would limit the amount of Federal dollars that states get to run the program. Congress has continued to reject those proposals.



Currently many states have long waiting lists for participation in Medicaid-funded community-based supports and services. Due to medical and advances in technology, people have longer life expectancies and often live with aging parents. As the population ages, the need for LTSS will increase for both people with I/DD and their caregivers. To meet these growing needs, Medicaid should be strengthened and other proposals should be developed to expand access to LTSS.

KEY ISSUES

Rebalancing: Rebalancing of long term supports and services means moving money from one type of setting to another and providing more funds for appropriate, permanent, integrated, community-based settings instead of more costly institutional settings. Rebalancing continues to be a focus of federal and state governments. Additional investments and changes to the Medicaid law to remove existing institutional bias (provisions of Medicaid law that favor institutions over community living) 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 encourages states to invest in home and community based services (HCBS) by providing federal funding for transitional services for individuals who wish to leave a nursing home or other institution.

Senators Portman (R-OH) and Cantwell (D-WA) and Representatives Guthrie (R-KY) and Dingell (D-MI) have introduced the EMPOWER Care Act (S. 548, H.R. 1342) to extend the Money Follows the Person Program. The Disability Integration Act (S. 117, H.R. 555) was introduced by Senators Schumer (D-NY) and Gardner (R-CO) and Representative Sensenbrenner (R-WI). The Disability Integration Act would remove the institutional bias and eliminate waiting lists for supports and services.

Key Points

Community Living

- Medicaid provides vital supports and services to people with disabilities.
- Fund Money Follows the Person and other programs that build capacity for community based services.
- Continue strong implementation of the HCBS Settings Rule.

Long Term Supports and Services (LTSS) Crisis: Much more needs to be done to address the growing and urgent need for an affordable and accessible system of LTSS that complements the Medicaid program. People should not have to become poor in order to be eligible to receive these important supports and services. Finding other ways to address the need for LTSS can save Medicaid dollars.

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 and 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.

RECOMMENDATIONS

- Congress must understand that Medicaid supports people with disabilities to live and work in their communities and Medicaid should not be cut or capped.
- Congress should address the nation’s need for an affordable, accessible system of long term supports and services.
- Members of Congress should act to remove the institutional bias of federal programs, eliminate waiting lists for LTSS, and to create a right to community living for individuals with disabilities, these issues are addressed in the Disability Integration Act (S. 117, H.R. 555).
- Congress should pass the EMPOWER Care Act (S. 548, H.R. 1342) to extend the Money Follows the Person Program.

For more information, please contact The Arc at (202) 783-2229, Association of University Centers on Disabilities at (301) 588-8252, American Association on Intellectual and Developmental Disabilities at (202) 387-1968, National Association of Councils on Developmental Disabilities at (202) 506-5813, Self Advocates Becoming Empowered at SABEnation@gmail.com, or United Cerebral Palsy at (202) 973-7185.