Issue At A Glance:

Home and Community-Based Services for People with Disabilities

This brief provides an introduction to home and community-based services that provide support for disabled people to live in their communities.

Introduction

Home and community-based services (HCBS) provide opportunities for seniors, disabled people, and people with low incomes covered by Medicaid to receive services in their own home or community rather than institutions. It is a type of long-term support service, and it was first implemented in 1983 via the addition of section 1915(c) to the Social Security Act. In the following decades, state options for HCBS have expanded, including the option to add HCBS to Medicaid state plans in 2005.[1] A major driver of this expansion was the *Olmstead v. L.C.* decision in 1999 that ruled that people with disabilities have the civil right to live in the community and must not be unnecessarily confined to an institution.[2] The goal of HCBS is to allow individuals to get support in their homes and communities to avoid being unlawfully placed in nursing homes, institutions, or intermediate care facilities.

There are over 4 million Medicaid enrollees who use HCBS to receive services in their own, family, or group homes.[3] Medicaid requires home health through a state plan with optional benefits such as private care and private nursing.[4] States can also target specific populations by providing HCBS waivers that offer additional services such as respite care, adult day care, personal assistance, transportation, supported employment, or therapies.

Types of HCBS Waivers and Benefit Options

1115 Demonstrations	These waivers allow states to test new projects and approaches that differ from the federal requirements of Medicaid. They can be used to tailor HCBS to the state's specific needs.[5,6]
1915(c) HCBS Waivers	These waivers allow states to tailor HCBS to the state's specific needs for people who would otherwise only be eligible for institutional care.[7]
1915(i) HCBS Benefit	This is an optional state plan benefit that provides some acute care and HCBS including respite, case management, supported employment, and environmental modifications.[8]
1915(j) HCBS Benefit	This optional state plan benefit allows states to give participants the ability to self-direct their personal assistant services.[9]
1915(k) CFC Option	This HCBS option known as Community First Choice allows states to provide attendant services under the state plan. Only 5 states offer this option.[10]

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The Importance of HCBS for Specific Disabilities

Allowing states to create HCBS waivers that target specific populations is important because specific populations will have different needs. For example, the needs of people with mental illness, brain injury, and intellectual or developmental disabilities (IDD) will vary. When comparing the benefits provided by HCBS waivers targeted to each of these specific populations in Colorado, for instance, there are several overlapping benefits but there are also unique benefits for each of the populations: the waiver targeted to people with brain injuries includes specific services such as behavioral management, education and independent living skills training while the waiver targeted to mental health includes mental health transition living home services and the waiver for IDD includes prevocational services and supported employment. All the waivers include things like specialized medical equipment, peer mentorship, and transportation.[11]

The disability population that has the most spending per person by Medicaid 1915 (c) waivers in FY 2020 was people with IDD.[12] However, one review found that people with IDD (along with people with traumatic brain injuries and veterans) were among a select group of the disability population identified within the literature to have difficulties with the availability of services that are specific to their needs. It was suggested that people with IDD often need speech-language therapy and physical therapy, but these services are not available in many states.[13] Another study found that addressing unmet needs with HCBS waivers was associated with fewer hospitalizations, suggesting better health.[14] Allowing states to use HCBS waivers to address unmet needs for specific populations can result in better health outcomes for these populations.

HCBS Final Rule

In 2014, the Centers for Medicare and Medicaid Services made several provisions to the Social Security Act to improve HCBS quality and access. The rule allows states to apply for a 5-year duration of both Medicaid HCBS waivers and Medicare managed care waivers so that the renewal process can be aligned for dually enrolled participants. States can combine targeted populations into one waiver to make administration more efficient. The requirements for the setting where recipients receive HCBS was changed under the rule to ensure that the setting qualifies as a home and is truly integrated into the community. The final rule also requires states to work with participants of HCBS waivers to ensure person-centered planning so that there is more autonomy in the process and that personal health goals are addressed. While the final rule was effective as of 2014, enforcement has been delayed. As of 2023, only 24 states reported that all their waivers comply with the rule.[15,16,17]

State Variability in HCBS

Eligibility

States can set eligibility criteria for HCBS state plans and waivers. For example, 1115 waiver eligibility is entirely under state control if the waiver promotes Medicaid objectives and is approved. States can limit eligibility to 1915(c) waivers based on specific diagnoses and geographical location, but a required institutional level of care must also be a criteria.[7,16] All state plan HCBS authorities such as 1915(c), (j), and (k) do not require an institutional level of care, but they require that enrollees meet all the other criteria for the Medicaid state plan and the financial eligibility for that state. 1915(i) state benefit criteria are set based on needs or specific populations.[8] 1915(j) requires concurrent enrollment in a state plan or 1915(c) waiver. 1915(k) requires concurrent state plan enrollment. These specific eligibility criteria make it easy to target HCBS services to specific populations, but they can limit access for a large proportion of the disability population.

Waiting Lists

Another aspect of HCBS 1915(c) waivers that states can control is waiting lists. Waiting lists are used when states limit the number of enrollees or funding for a specific waiver. One significant factor that states control is whether individuals are screened for waiver eligibility before or after being added to a waiting list.[3] This can result in longer waiting lists when eligibility is not pre-screened. The number of people on HCBS waiting lists in the U.S. in 2023 was 692,000 with an average wait time of 36 months per person.[3] While waiting lists are useful for managing resources and costs, if they are too long, they can hinder access to HCBS services.

Funding

HCBS are funded by federal and state governments. In 2010, it was found that states vary greatly in the estimated cost of each of their 1915(c) waivers.[18] This is partly due to the state's ability to limit waiver costs. Variations in cost show that states place more importance on certain waivers as compared to others. For example, they may put more funding towards a waiver that supports the disability population that is most prevalent in their state. States can offer comprehensive waivers that include many benefits or provide support waivers. Spending was found to be less on support waivers when looking at waivers for IDD.[18] This is beneficial to the overall budget but could restrict HCBS resources.

Workforce Availability

Workforce availability can also greatly affect access to HCBS. Some states have made incentives to increase their home care workforce while others have not. It is necessary that states maintain a workforce that is sufficient to provide services to their disability population.[19]

Conclusion

HCBS are necessary to ensure that people with disabilities receive the support they need to live fulfilling lives in their communities. It is a right of all Americans to be included in society. Each state has the ability to uniquely tailor these services to their distinct disability population and the specific needs of the different people in that population. While there is much variability between states in the specific services they provide, the regulations they implement, and the resources they have access to when implementing HCBS plans, it is important that states approach the process of tailoring and expanding their HCBS with a person-centered approach. Sufficient access and availability to HCBS have the ability to improve health outcomes for the millions of people who use these services. It is imperative that as policies continue to change regarding HCBS, efforts are made to provide equitable and inclusive care across the nation.

Did you know?

The Southern region of the United States has the largest percentage of the population with a disability (13.8%) followed by the Midwest (13.1%), the Northeast (12.3%), and the West (12.1%).[20]

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