

Care Can't Wait

How Do Inadequate Home- and
Community-Based Services Affect
Community Living and Health Outcomes?



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Introduction and Background

About 12 million people with disabilities and older adults in the United States need LTSS, or long-term services and supports—health and social services for people who need help with eating, bathing, medication management, meal preparation, mobility, and other activities of daily living. Medicaid is the primary source of funding for these services.

Most recipients prefer to receive LTSS at home, rather than in institutions like nursing homes. And this goes beyond simple preference: the Americans with Disabilities Act (ADA), as well as the *Olmstead v. L.C.* Supreme Court decision, affirms people’s right to live in the most integrated setting that meets their needs. Medicaid offers an alternative to institutional care, called Home- and Community-Based Services, or HCBS. These services include in-home personal care, transportation, assistive technology, adult daycares, home modifications, and supported employment. Since HCBS ensures that people receive the help they need within an integrated setting, it’s one way to uphold the rights guaranteed in the ADA and *Olmstead*. High-quality HCBS allows people to direct their services and define their goals, live independently, participate in the community, and age with their human dignity intact.


But not everyone who needs HCBS receives them: state Medicaid programs must pay for nursing-home care, but they are not required to cover HCBS. Although access to these services has increased over the past few decades, only 56% of total Medicaid spending on LTSS goes to HCBS.

Also, states have a great deal of control over their Medicaid systems, meaning that states’ programs, services, and eligibility requirements can vary significantly—and states also control how many eligible people can receive services through enrollment caps and waiting lists. In the US, over 820,000 people are on waiting lists for services, and the average wait time is three years or more. When older adults and people with disabilities don’t receive the services they need, their health and quality of life decline. Earlier studies found a connection between unmet HCBS needs



Most states cap enrollment in their Medicaid home- and community-based service programs and maintain wait lists.

Nationally, over 820,000 people are on HCBS wait lists.



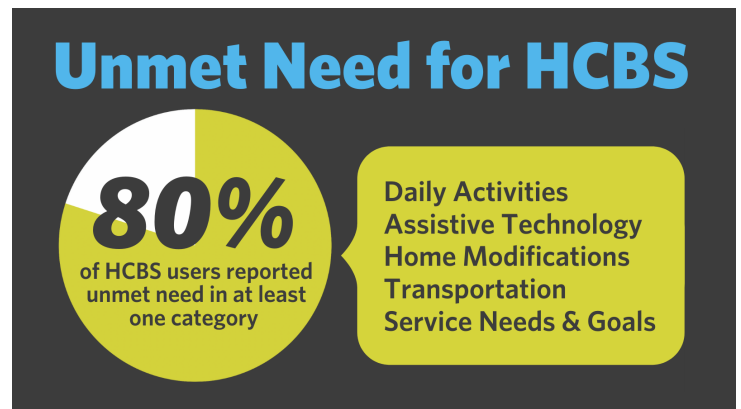
and a variety of adverse outcomes, including hospitalization, institutionalization, and even death.

Because these adverse outcomes have wide-ranging effects both on individual service recipients and the community at large, we conducted a study with two goals: learning how many people needed more services than they were receiving, and understanding the connection between unmet HCBS needs and health and community living outcomes. We examined survey data on adults who were over the age of 65 or who had physical disabilities and were receiving Medicaid HCBS in 13 different states.

Findings

Here's what we learned from the study:

1. About 80% of the survey respondents had at least one unmet need for self-care and other daily activities, services that met their needs and goals, assistive technology, home modifications, or transportation.
2. The most common unmet needs were for assistive technology and home modifications.
3. People with unmet HCBS needs were younger on average than those whose needs were fully met.
4. Non-Hispanic white HCBS users were more likely to have all their needs met than people of other racial and ethnic groups.
5. People with unmet HCBS needs were more likely to live at home or in senior living, and they were also more likely to live alone.
6. HCBS users with any unmet needs were more likely to say that they were in poor health.
7. Compared with those whose HCBS needs were met, people with at least one unmet need were more likely to visit the emergency room (52% versus 34%) or stay overnight at a hospital or rehab center (36% versus 24%).



8. People who had no unmet HCBS needs were more likely to say that they felt they could be active in the community, spend time with their family and friends, be satisfied with their daily activities, and feel in control of their lives.
9. People without unmet HCBS needs were more likely to receive preventive care services, such as physical and dental exams.

Where do we go next?

Although our study didn't examine why HCBS recipients had unmet needs, it still showed possible contributors to this shortfall:

1. For example, states' HCBS programs are optional, limited, and restricted, meaning that people who would otherwise receive services are on long waiting lists.
2. Systemic racial and ethnic discrimination, as well as geographic isolation, can also make it more difficult to receive home-based services.
3. Because there is more demand for well-qualified direct-care workers than agencies can supply, clients may not receive as much help as they would otherwise, especially if they can't receive support from family members. But even if agencies do match HCBS users with direct-care workers, they may not receive the support they need for very long—turnover rates and job vacancies are high among these workers because they typically receive limited training, low wages, and scanty benefits.
4. Medicaid requires person-centered planning for everyone receiving HCBS. Person-centered planning is a service model that helps recipients make decisions about the services they use based on their needs, values, goals, and preferences. But variations in how states carry out person-centered planning can make it more difficult to ensure that HCBS recipients get the help they need.

Because unmet need for HCBS was consistently associated with poorer health and community living outcomes, researchers, policymakers, advocates, and service providers must work to find solutions that ensure that people receive the care they need in the community—and avoid impersonal congregate settings.

State and federal policymakers can make steps toward improving access to HCBS, including centralized healthcare plans—for example, Managed LTSS—that combine acute care and

long-term supports. Programs can also track how much recipients' needs are being met—and whether the services they receive help them reach their goals, feel in control over their lives, and stay connected with the people who matter most.

Credit

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How to Cite This Brief

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