HCBS 101: Why Home and Community-Based Services Matter to People With Disabilities and Their Families

For many people with disabilities, the ability to live at home, go to school, work, participate in the community, and remain connected to family and friends depends on support. That support may include help with personal care, communication, transportation, employment, behavioral supports, respite for family caregivers, home modifications, or services that help a person build and maintain daily living skills.

Many of these supports are provided through Medicaid Home and Community-Based Services, often called HCBS.

HCBS can be confusing because these services are covered under Medicaid, but they are not the same as ordinary medical care. They are also different from the Medicaid coverage many people think of when they hear the word "Medicaid," such as doctor visits, hospital care, prescriptions, therapy, or nursing home care.

At their core, HCBS help make community living possible.

What Are HCBS?

HCBS are Medicaid-funded services that help people with disabilities and older adults receive care and support outside of institutions.

Instead of requiring a person to live in a nursing home, intermediate care facility, developmental center, or other institutional setting to receive needed support, HCBS can help make it possible for the person to live at home or in another community setting.

Depending on the state and the particular program, HCBS may include:

- **Personal care assistance**
- **Respite for parents and family caregivers**
- **Habilitation services that help a person learn or maintain daily living skills**
- **Supported employment**
- **Day habilitation or community participation services**
- **Behavioral supports**
- **Assistive technology**
- **Home or vehicle modifications**
- **Transportation**
- **Care coordination or service coordination**
- **Other services designed to allow the person to live, work, learn, and participate in their community**

The exact services available depend on the state, the program, the person's eligibility, and the person's assessed needs.

The important point is this: HCBS can allow Medicaid to fund services that help people live and participate in the community rather than in institutions.

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Waivers Are Often the Approach Used to Provide HCBS

Many HCBS programs are called “waivers” because the federal government allows states to waive certain Medicaid rules to provide support services in the community.

Historically, Medicaid’s long-term services and supports were heavily oriented toward institutional care. In 1981, Congress added Section 1915(c) of the Social Security Act, allowing states, with federal approval, to waive certain Medicaid requirements and provide HCBS to individuals who would otherwise require an institutional level of care.

The important point is this: HCBS can allow Medicaid to fund services that help people live and participate in the community rather than in institutions. HCBS often cover the practical, daily supports that make community living possible, even if these services are not always “medical” in the narrow sense.

Why HCBS Matter for Children, Youth, and Younger Adults With Disabilities

When people hear about long-term care, they often think first about older adults and nursing homes. HCBS are important for older adults, but they are also central to the disability service system for children, transition-age youth, and younger adults.

For a child with disabilities, HCBS may help the child remain at home with family rather than entering a facility.

For a teenager or young adult, HCBS may support the transition from school to adult services, employment, day programming, or more independent living.

For an adult with intellectual or developmental disabilities, HCBS may provide the ongoing supports needed to live in an apartment, a family home, a certified residence, or another community setting.

For a person with significant physical disabilities, HCBS may provide personal care, assistive technology, transportation, or modifications that make ordinary daily life possible.

For family caregivers, HCBS may provide respite and support that help prevent caregiver burnout and allow families to continue caring for loved ones at home.

HCBS are not a luxury. For many people with disabilities, they are the infrastructure that makes community life possible.

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Why Access to HCBS Can Be Fragile

One of the most important things to understand about HCBS is that these programs are not always available to everyone who needs them.

Unlike some Medicaid services that states are required to provide, many HCBS programs are optional. States may decide which waiver programs to operate, what services to include, how many people may enroll, and how much funding to allocate.

As a result, a person may meet the disability or care needs criteria for HCBS but still be placed on a waiting list. In some states, people wait months or years for services. Families may spend years trying to understand eligibility rules, complete applications, obtain evaluations, and secure a waiver slot.

This is one reason HCBS can feel confusing and frustrating. The issue is often not just whether a person needs services. The issue may also be whether those services are actually available in the individual’s state of residence.

Why This Matters Now

Recent federal Medicaid changes under the One Big Beautiful Bill Act (OBBBA) (P.L. 119-21), including significant cuts in federal funding, have increased concern about state Medicaid budgets and the future of optional Medicaid services, including HCBS.

Medicaid is funded by both the federal government and the states, but Medicaid services and supports are administered by the states. States must ensure that Medicaid covers certain care and treatment.

Because HCBS programs are usually optional, state-administered, and dependent on state funding choices, reductions in federal Medicaid funding, new eligibility requirements, broader budget pressures, and competing obligations to fund mandatory Medicaid services may lead some states to consider changes to HCBS programs.

Those changes could include limits on the number of people who can receive services, longer waiting lists, reductions in covered services, reduced service hours, lower provider payment rates, provider shortages, more difficult application or renewal procedures, or greater pressure on families to provide unpaid care.

This does not mean every state will make the same choices. HCBS programs are state-specific, and advocacy will also need to be state-specific. But families, attorneys, and advocates should understand what HCBS are now so they can recognize what is at stake if changes are proposed.

What Families May Notice

Families do not need to know every Medicaid rule or waiver authority to recognize when services may be at risk. They should pay attention to practical changes in the services the person receives or is trying to access.

Families may not see state policy decisions directly, but they feel the impact when services are delayed, reduced, denied, or unavailable. Many of these access and service-delivery problems were already being experienced by individuals and families across the country before the enactment of OBBBA. Changes following OBBBA may compound existing challenges.

Pay attention to changes, including:

- **Services are harder to obtain or are cut completely**
- **Assessments or approvals are delayed**
- **Service hours are reduced**
- **Respite, personal care, habilitation, supported employment, transportation, or behavioral supports are limited**
- **Provider agencies are short-staffed or unable to deliver approved services**
- **Waiting lists are growing**
- **Families are told that services exist but are not available in practice**
- **People end up in more restrictive settings because community supports are unavailable**

For Attorneys and Advocates

Special needs planning attorneys should not expect clients and families to know whether a service is funded through a specific HCBS waiver, another Medicaid pathway, a state plan service, or a state-funded disability program.

The attorney's role is to gather that practical information and then research or confirm how those services are funded and administered in that state.

Once the attorney understands what the client is receiving and from whom, the attorney can identify the relevant state program, determine whether the services are funded through an HCBS waiver or another Medicaid pathway, and evaluate how the services fit into the broader special needs plan.

The Bottom Line

HCBS help people with disabilities live in their homes and communities rather than in institutions. For children, youth, and younger adults with disabilities, HCBS may support family life, school-to-adult transition, employment, independence, safety, and community participation.

HCBS are different from traditional Medicaid medical coverage because they often fund the daily supports that make community living possible. But because many HCBS programs are optional and state-administered, access can be limited by funding, eligibility rules, enrollment caps, waiting lists, provider shortages, and service restrictions.

As states respond to Medicaid funding pressures — including those related to OBBBA — families, advocates, and attorneys need to understand what HCBS are and why they matter.

HCBS are more than a category of Medicaid-funded services. For many people with disabilities, they are the bridge between institutional care and a life in the community.

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