

## Understanding Home and Community-Based Services May 2025

Home and Community-Based Services (HCBS) are programs that help people with disabilities, chronic health conditions, and aging-related needs live in their own homes and communities, rather than being placed in nursing homes or other institutions. HCBS programs include both waivers (special programs with extra services for people who need them) and other supports like personal care, day programs, and caregiver help.

Historically, services were mostly offered in institutions. Starting in the 1970s, lawsuits and advocacy pushed states to shift support to community settings. These services ensure that everyone can live with dignity, choice, and belonging in their communities.

### How HCBS Works in Massachusetts

Medicaid, known in Massachusetts as MassHealth, is the foundation of both waiver programs and other home and community-based services (HCBS). The cost of MassHealth is shared by the state and federal governments, with the federal government reimbursing Massachusetts for more than half of what the state spends.

Protecting Medicaid means protecting access to these critical supports. Cuts to Medicaid jeopardize the availability of HCBS programs, threatening people's ability to choose where and how they live. Strengthening Medicaid is essential to upholding dignity, choice, and community inclusion for everyone.

## **HCBS Services**

Massachusetts offers important HCBS programs funded through Medicaid and state agencies.

| Program                               | What It Does  |
|---------------------------------------|---|
| Personal Care Attendant (PCA) Program | Helps people hire aides for daily living tasks              |
| Adult Foster Care                     | Supports people living with trained caregivers in a home    |
| Group Adult Foster Care               | Helps people in group living settings                       |
| Adult Day Health                      | Provides daytime nursing care, meals, and social activities |
| Behavioral Health Services            | Supports mental health needs in home and community settings |
| Day Habilitation Services             | Helps people with disabilities build independence skills    |
| Family Support Services (DDS)         | Offers flexible support for families                        |
| MassHealth Community Partners Program | Coordinates health and social services for complex needs    |

#### Waivers

Waivers allow Massachusetts to offer extra services and flexible supports beyond what traditional Medicaid normally covers. HCBS waivers are how the state supports people who need long-term care to live more independently. These waivers allow the state to "waive" certain federal Medicaid rules, such as requiring institutional care, so eligible individuals can get the support they need in less restrictive settings.



These programs give states more flexibility in how they offer services. For example, Massachusetts can:

- Choose who qualifies for each waiver program (provided they meet federal guidelines)
- Limit how many people can be in each program
- Offer extra services that traditional MassHealth doesn't cover
- Adjust the usual income and asset rules to help more people qualify

# Why Do HCBS Programs Matter?

- **Dignity:** HCBS honors the right to live independently with support.
- **Community**: These services allow people to stay connected to family, school, work, and friendships.
- **Cost:** Community-based care often costs less than institutional care.
- **Civil Rights:** Protecting HCBS protects the promise of the Americans with Disabilities Act and landmark lawsuits.

## Example: Meet "Lucas," age 9, from Worcester, MA

Lucas is autistic and has epilepsy. He's non-speaking and has high support needs. Right now, thanks to an HCBS waiver through MassHealth, his family receives several critical supports:

- A personal care attendant (PCA) comes every afternoon to help Lucas with hygiene, dressing, and sensory regulation after school. An occupational therapist works with Lucas and his family in their home on motor development twice a week, funded under a waiver.
- His mom, a single parent, uses limited respite care hours to pick up groceries, attend her own doctor appointments, and take breaks that keep her from burning out.

If Medicaid cuts are implemented:

- His waiver slot may be frozen, and he could lose his current services. His mother could lose her job without PCA or respite coverage.
- Lucas could end up in a more restrictive setting.

## What Can We Do?

If you're concerned about how these changes might affect you or your loved ones:

- **Contact your legislators:** Your legislators can influence policy decisions. Find your federal legislators <u>here</u> and your state legislators <u>here</u> and reach out to share your story.
- Join us: Advocacy efforts are more effective when individuals band together. Join The Arc of Massachusetts' <u>Action Center</u> to learn about upcoming advocacy opportunities.
- We are here to help: <u>The Arc of Massachusetts</u> can play a key role in helping families navigate changes in policies and regulations, by providing resources, guidance, and support for families of individuals with disabilities.

#### For More Information

Please reach out for more detailed information by contacting Nora Bent, Director of Government Affairs and Strategic Partnerships (<u>nbent@arcmass.org</u>).