



MDDC Policy Spotlight: Medicaid

February, 2025

Background

The Massachusetts Developmental Disabilities Council (MDDC) is a state agency funded by the federal government. Every state in the United States has a Developmental Disabilities Council. Our mission is to support people with developmental disabilities (DD) and their families across Massachusetts.

Developmental disability is an “umbrella term” that includes intellectual, physical, and sensory disabilities. Developmental disabilities present before a person turns 22 and are likely to affect a person for their entire life. Some examples include Autism, cerebral palsy, and intellectual disabilities like Down syndrome. Sometimes, this category is described as “Intellectual and Developmental Disabilities” or IDD because most people with intellectual disabilities fall under the DD category. However, there are many people with developmental disabilities that do not have intellectual impairments.

What is Medicaid?

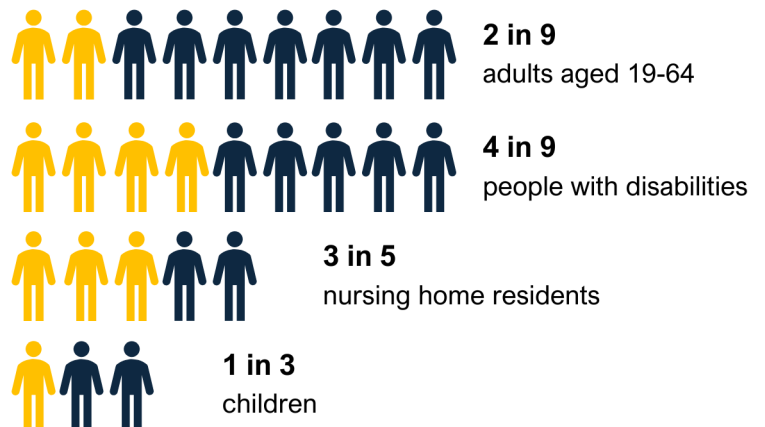
Medicaid is the largest public provider of healthcare and long-term services and supports (LTSS) in the United States. It is also an important partnership between federal and state governments. The federal government sets rules and provides funding so states can ensure that certain groups of people can access Medicaid services. One population that Medicaid serves is people with disabilities, including people with intellectual and developmental disabilities (IDD). Currently, Medicaid serves over 77 million people nationally. At least 10 million of these enrollees are children and adults with disabilities.¹

Who uses Medicaid in Massachusetts?

Here in Massachusetts, our Medicaid program is called MassHealth. The federal government funds about 61% of our state’s Medicaid, and Massachusetts covers the remaining 39% of costs.² Around **1.7 million** people are enrolled in MassHealth for services and supports.

About **29%** of these Medicaid enrollees are elderly individuals or people with disabilities.

In Massachusetts, Medicaid covers ³:



Medicaid provides Home and Community Based Services (HCBS)

Over 365,000 adults in Massachusetts need LTSS⁴. LTSS that are provided to people living in the community are called Home and Community-Based Services (HCBS). HCBS makes up about 70% of all Medicaid spending on LTSS in Massachusetts.⁵ **This is important because federal regulations⁶ and Supreme Court rulings⁷ require that people with disabilities be supported to live in the most integrated settings possible.**

Some examples of Medicaid-funded HCBS include:

- **Direct Support Professionals (DSP) and Personal Care Attendants (PCA)** who assist people with activities of daily life like getting out of bed, bathing, getting dressed, and preparing meals;
- **Employment services** like job coaching and supported employment;
- **Home modifications and assistive technology** like ramps, door widenings, and augmentative and alternative communication (AAC) devices;
- **Support to family caregivers** like respite;
- **Payment for certain services in schools to support learning** (i.e., speech, occupational therapy (OT), physical therapy (PT), and behavioral supports);
- **Accessible transportation** like rides to and from medical appointments.

What Medicaid services are required?

There are two categories of Medicaid services: Mandatory and Non-Mandatory.¹

1. **Mandatory** services are required by law. This includes healthcare services like doctor visits, medical care in hospitals, and LTSS that are provided in nursing homes or institutions.
2. **Non-mandatory** services are optional and vary state by state. This includes services like dental care and some therapies. Most HCBS are provided through non-mandatory Medicaid waiver programs.

Non-mandatory services like HCBS are most likely to be affected by any cuts to Medicaid.

What is Medicaid expansion?

In 2014, Medicaid was expanded as part of the Affordable Care Act (ACA). States had the option of expanding coverage so more people who do not make a lot of money could access Medicaid. 41 states, including Massachusetts, chose to adopt “Medicaid Expansion.”³ This helped about 17 million more Americans, including many people with disabilities, get access to Medicaid services.¹ In Massachusetts, the federal government pays 50% of the cost for traditional Medicaid, but 90% of the cost for Medicaid expansion.³

Medicaid Expansion populations have a higher risk of being affected by cuts to Medicaid.

Medicaid is a lifeline for people with IDD

Medicaid services and supports help people with IDD live in the community and stay out of costly institutions. Medicaid helps people be productive members of society and have freedom to choose how they live their lives. **Freedom is a universal value we share as Americans, and this includes people with disabilities.**

Many people with IDD in Massachusetts are waiting to access services and supports that they need to live as independently as possible in the community.⁸ Nationally, there were nearly 700,000 individuals on waitlists to HCBS services in 2023.⁹ Most people waiting have IDD. Massachusetts does not share “waiting lists” with the public, so we do not know the exact number of people waiting for services in our state.

How could changes to Medicaid affect people with IDD?

If there are cuts to Medicaid, even more people with IDD will not get the services and supports they need.¹⁰ Non-mandatory programs, like HCBS waivers, could receive less funding. This includes programs that help people live in their homes and work in their communities. This means that:

- More people may be waiting to access basic healthcare and LTSS that allow them to live their lives.
- More people may lose community jobs or be unable to work without supported employment services .
- More people with IDD may be at higher risk for living in institutions, which costs more money than HCBS.¹¹
- Fewer children with IDD may have access to services they need to succeed in school and to prepare for future employment and greater independence.
- Parents and caregivers of people with IDD may have no options for formal supports. They may have to leave jobs to care for their loved ones. Cuts to Medicaid may cause financial hardships.

People with IDD are citizens of our nation. Many can and want to work, and live meaningful lives in our communities. Medicaid services and supports allow them to do so.

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Additional Resources

- **Autistic Self-Advocacy Network Guide to Medicaid**

autisticadvocacy.org/policy/toolkits/medicaid/

- **NACDD Medicaid Fact Sheet**

nacdd.org/nacdd-medicaid-fact-sheet/

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