

MDDC Policy Spotlight: Direct Care Workforce

June 2025

Background

The workforce crisis is jeopardizing the lives of people with intellectual and developmental disabilities (IDD) and their families. Low wages and a shortage of workers have made it very hard for people with disabilities to have the care and support they need to live in the community. The crisis has reached serious levels and was made worse by the COVID-19 pandemic.¹ The lack of workforce and proposed Medicaid cuts threatens life in the community for too many people with IDD.^{2,3}



Medicaid and the workforce crisis

- Medicaid is a federal and state partnership and the primary payer for long-term services and supports (LTSS) for people with IDD.⁴
- Home and community based services (HCBS) are a type of waivered LTSS. HCBS gives people with disabilities access to services in their own home or community rather than being placed in costly institutions or other isolated settings.⁵
- For many years now, there has not been enough funding for Medicaid HCBS and other state programs that serve people with IDD.⁴
- Low Medicaid rates have meant low wages for the workers that provide direct care to people with disabilities.⁶
- Federal cuts to Medicaid would likely increase costs to states.^{7,8}
- States would not be able to make up funding gaps. Reduced funding would devastate people with IDD and their families leaving them unable to hire and keep workers.⁹



Because of their low wages, more than one in four direct care workers rely on Medicaid for their own health coverage.⁶

Workers that support people with disabilities

The paid workers that support people with IDD go by many different names including Direct Support Professional (DSP), Direct Care Worker (DCW), Personal Care Attendant (PCA), Home Healthcare Aide (HHA), etc. These titles are often used interchangeably.

These professionals are responsible for providing a wide range of support to people with IDD which include many of the things we all do every day. They are dedicated workers and have a high level of responsibility. These workers not only make sure the basic needs of people with IDD are met, they also are responsible for their health, safety, and wellbeing. Some examples of their responsibilities include:

- Supporting Access to Meaningful Community Inclusion They help individuals with IDD become integrated into their communities, through employment, social, recreational, civic activities, etc.
- Providing Essential Supports They assist with activities of daily living (ADLs), such as personal care, meal preparation/eating, and cleaning. DSPs may also provide transportation, as well as supporting individuals in finding and maintaining employment.
- Supporting Learning and Skill Development They play a crucial role in teaching new skills, promoting independence, and helping individuals achieve their goals.
- Administrative Duties Many people with IDD live in settings funded by Medicaid which means strict policies must be followed to make sure individuals receive quality supports and care. This means these workers have even more responsibility to comply with rules, submit documentation, navigate and communicate with healthcare professionals, etc.



- Working in Various Settings They may work in homes, group homes, community job sites, vocational programs, and other locations.
- Managing a Complex Role The role of these workers goes beyond basic caregiving, requiring skills in communication, problem-solving, behavioral support, and crisis prevention.¹¹

The workforce crisis

In the United States, there is a crisis within the direct care workforce. The underlying issues include:



Human shortage

There is a nationwide shortage of workers, impacting the quality and availability of services for people with IDD.¹²



Direct care workers often earn low wages, making it difficult to attract and retain qualified professionals.¹²



High Turnover

The combination of low wages and demanding work conditions leads to high turnover rates, which can negatively impact on the quality of care and the stability of individuals with IDD.^{3,13}



Underinvestment

Long-term low funding of Medicaid and other funding sources have contributed to low reimbursement rates and the inability of providers to pay workers a living wage.³



90% of organizations that employ direct care workers reported experiencing staffing shortages.³



69% of case management providers reported turning away new referrals.³



39% of organizations reported they were discontinuing programs due to shortages.³

Workforce crisis solutions

- Adequate Funding: Independent expert analysis has shown that addressing this crisis would require increased funding for Medicaid and other programs that support people with IDD. Adequate funding would allow providers to pay these workers a living wage and offer better benefits.³
- Improved Training and Education: Investing in training and education for these workers can help improve their skills and knowledge, leading to better outcomes for individuals with IDD.¹⁴
- **Promoting the Profession:** Efforts to promote this profession as a rewarding and meaningful career path can help attract more people to the field.
- **Supporting Retention:** Implementing strategies to support these direct care workers, such as providing opportunities for professional development, mentorship, and career advancement, can help improve retention rates.¹⁰

Massachusetts Stories - Lauren & Gabe

The workforce crisis has impacted MA day habilitation providers making it more difficult to find and retain staff. These providers can't offer competitive pay to attract enough workers. This has caused more than 1,000 people with disabilities to be unable to enroll in day habilitation programs as of October 2024, leading to mental and physical regression.¹⁵

Each week Lauren is stuck in her MA group home while her two roommates leave and attend day habilitation programs in the community. Lauren has complex intellectual and developmental disabilities and experiences a seizure disorder. Lauren's skills have regressed due to lack of activity and staffing shortages. The workforce crisis has meant extended isolation for people like Lauren and limited to no access to the community. She now has more difficulty feeding herself. Gabe Raagas, a 32-year-old with autism, has watched his four housemates leave for their day hab programs as he sat on a waiting list. As his housemates were attending their programs, Gabe spent his days shopping and attending an amusement park with his caregiver. As his family explains, people with disabilities deserve a community outside of their group homes and access to social opportunities. In March 2025, Gabe was accepted into a day hab program.¹⁵

Relevant Bills

In Massachusetts, bills have been introduced in past and current legislative sessions related to the direct care workforce, including:

H.2104/S.1325 - An Act relative to meeting human service demand by modernizing incentives for the direct care workforce.

- This legislation would require salaries for direct care staff and direct support professionals working in human services to meet or exceed the 75th percentile for comparable jobs, based on data from the Bureau of Labor Statistics.
- It also mandates salary increases for other personnel categories, including frontline supervisors, directors, and clinicians, but excludes top-level executives such as CEOs and CFOs from these adjustments.
- Reduced or delayed funding for social services or long-term support programs would not be allowed under this legislation.

H.2104/S.1325 - An Act relative to meeting human service demand by modernizing incentives for the direct care workforce.

- Due to the difficulty of finding staff to care for their loved ones with disabilities, some family members have had to step in and fill in the gaps.
- This legislation would broaden the criteria for MassHealth to pay family members for their caregiving service. Eligibility would extend to:
 - Legally liable family members, including biological, adoptive, foster, or stepparents,
 - Legal guardians,
 - Powers of attorney/healthcare powers of attorney, and
 - Adult children.
- The bill also mandates that the Executive Office of Health and Human Services submit a state plan amendment or waiver application as necessary to facilitate the inclusion of these individuals as paid caregivers under MassHealth.
- By providing this incentive, more people with disabilities will be able to live where they want in their community.

About the MDDC

The Massachusetts Developmental Disabilities Council (MDDC) is an independent agency, funded by the federal government, dedicated to empowering people with developmental disabilities and their families to enjoy full productive lives by promoting self-sufficiency, community inclusion & opportunity.



The MDDC works to improve the system of supports for individuals with developmental disabilities and their families by bringing advocates together with policymakers to be sure people with developmental disabilities are included in policy decisions that impact their lives.

The MDDC also serves as an objective resource to inform public policy at the local, state and federal levels, to better meet the needs of individuals with developmental disabilities and their families.

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