



# MDDC Policy Spotlight: Disability in Healthcare

## May, 2025

### Background

Access to quality healthcare is vital to all Americans, including people with intellectual and developmental disabilities (IDD). Without adequate and accessible healthcare, people with IDD can experience significant illness and injury that impact the wellbeing of their everyday lives. Across the country, people with disabilities do not get the same treatment throughout the healthcare system as people without disabilities.<sup>2</sup>

**4x**  
**people with disabilities are  
four times more likely to  
experience worse health  
nationwide.<sup>18</sup>**

### Why is healthcare a key issue to people with IDD?

People with IDD often have many complex health needs and rely on the services and supports of the healthcare system to keep them healthy.<sup>18</sup> All residents of Massachusetts, regardless of disability status deserve to live healthy, productive lives alongside their friends and family. Access to quality healthcare is vital for this to happen. Implementing policies to protect, educate, and support individuals with IDD and healthcare professionals can help strengthen the overall health and delivery of care to all those in need.



Image Credit: Anna Shvets

### Who is this impacting?

- There are nearly 800,000 people with disabilities living throughout Massachusetts.<sup>3</sup> Individuals with disabilities often face barriers when they are using the healthcare system.
- People with IDD often have caregivers, family, and friends who support them in daily activities. Caregivers also face obstacles and often don't feel heard during processes and procedures.<sup>4</sup>
- Training for healthcare providers helps them to provide the best care and wellbeing to patients with IDD who may have specific health needs.<sup>4,8-10</sup>

## How are people with IDD treated in healthcare settings?

People with disabilities, and people with IDD in particular, are often dissatisfied with the treatment they receive.<sup>18</sup>

We know that people with disabilities **can** live good lives just like anyone else.<sup>6,7</sup> Having a disability does not determine your quality of life, and it is important for **all** people to feel comfortable with their doctors and receive good care so they can be as healthy and productive as possible.

Too many doctors believe the lives of people with disabilities are not as good as people without disabilities.<sup>8</sup> Doctors themselves report that they face challenges and view people with disabilities differently when treating them.<sup>8-11</sup>

### People with IDD have reported that healthcare providers were less likely to:<sup>5</sup>



**Listen carefully.**

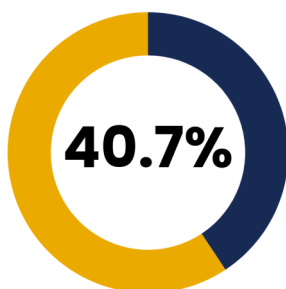
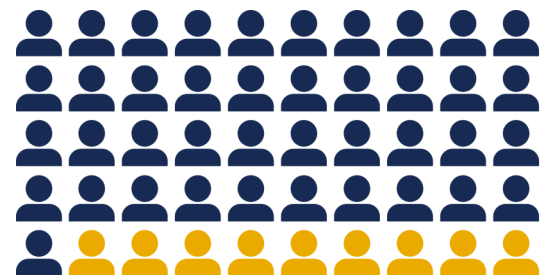


**Explain things in simple terms.**

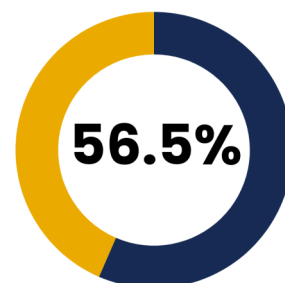


**Show them the same respect as people without disabilities.**

**When asked, about 82% of physicians think that people with disabilities have a worse quality of life.<sup>8</sup>**



**Only 40.7% of physicians felt “very confident” in their ability to provide the same quality of care to patients with disabilities.<sup>8-11</sup>**



**Just 56.5% of physicians strongly agreed that their clinics welcomed people with disabilities.<sup>8</sup>**

## Crisis Standards of Care

People with disabilities had less access to healthcare during the COVID-19 pandemic due to the use of Crisis Standards of Care.

- “Crisis Standards of Care” are rules about how hospitals share life-saving care and equipment during emergencies, like the COVID-19 pandemic.
- Many state governments set rules that meant people with disabilities were pushed to the back of the line, and did not get needed care or access to ventilators.<sup>12-14</sup> These types of practices in health settings meant that people with IDD were more likely to pass away during the COVID-19 pandemic than those without IDD.<sup>15</sup>



Image Credit: Pixabay

## Real Life Impact: Holly Simione



Holly Simione is a former chairperson of the MDDC. A mother of two, Holly's world was turned upside down when her daughter Elizabeth passed away due to discrimination during a trip to the hospital.

Massachusetts adopted, but did not implement Crisis Standards of Care during the COVID-19 pandemic. Even still, doctors treating Elizabeth assigned a lower priority to her treatment and care.

Staff did not listen to Holly's concerns, did not properly explain the treatments they were providing, and put less value on Elizabeth's life due to her disabilities, leading to a lack of critical care.

**“We cannot continue to ignore the bias based systems that determine who can live, and who dies. That yellow sticker was placed over my daughter's bed to remind every doctor she was not worth saving. It was never explained, or discussed. She was 18 years old and her life had value.”**

# What policies impact people with disabilities in healthcare settings?

- State and federal agencies know that people with disabilities are treated differently in the healthcare system.
- In recent years, different agencies have made changes to try to protect people with disabilities throughout healthcare settings:
  - In 2023, the National Institute of Health (NIH) designated people with disabilities as a “health disparity population.”<sup>16</sup> This was intended to provide more resources for research and programs that will help people with disabilities have better healthcare.
  - In 2024, the U.S. Department of Health and Human Services announced updates to Section 504 of the Rehabilitation Act. These updates are supposed to help protect people with disabilities and improve access to healthcare services and programs.<sup>17</sup>
- Given recent staffing changes at the NIH and the lawsuit challenging Section 504, state protections would help ensure more equitable access to healthcare for people with disabilities.

The MA Legislature has been considering legislation to prevent discrimination against people with disabilities and ensure access to healthcare settings.

## **H.1360/S.869 – An Act relative to preventing discrimination against persons with disabilities in the provision of health care**

- This bill would amend chapter 151B by replacing the term "handicap" with "disability."
- It prohibits presumptions about disability that could interfere with the quality of care that providers give to people with disabilities, including assumptions about quality of life.
  - It would also prohibit the use of metrics that value quality of life when determining the order and priority of care of all patients.
- Healthcare providers are not allowed to require “orders not to resuscitate” or other forms of care directives for people with disabilities or their caregivers.

## H.242/S.149 – An Act to enhance standards of care for those with autism and intellectual and developmental disabilities

- This legislation would make the Executive Office of Health and Human Services create a statewide plan to make training, education, and standards of care for healthcare providers to use when treating and caring for patients with IDD.
- This policy would also create a statewide advisory committee that is made up of stakeholders to make recommendations to the state plan's content.
- These recommendations will be about:
  1. Continuing education requirements for applicable healthcare,
  2. Standards for improving assessment and diagnosis for patients during routine outpatient primary care examinations, and
  3. The adoption of appropriate continuing education requirements related to intellectual and developmental disabilities as part of licensure renewals.

### 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.

## Contacts

### **Joshua Gladstone, Disability Policy Specialist**

**Email:** Joshua.Gladstone@mass.gov

**Phone:** (617) 770-7676 ext. 115

### **Kaitlin Stober, Policy Research Associate**

**Email:** Kaitlin.Stober@mass.gov

**Phone:** (617) 770-7676 ext. 121

**Visit the MDDC online:** [mass.gov/mddc](https://mass.gov/mddc)

**Follow the MDDC on social media:**   @MassDDCouncil  @MA\_DDC

## Sources

1. Altman BM, Bernstein A. Disability and Health in the United States, 2001-2005. Hyattsville, MD: National Center for Health Statistics; 2008. Google Scholar
2. Iezzoni LI. Disability Disparities and Ableism in Medicine. ABC of Equality, Diversity and Inclusion in Healthcare. 2023;1:61.
3. download MRC
4. Charles ML. Communication experiences of family caregivers of hospitalized adults with intellectual and developmental disabilities—A qualitative study. Nursing Open. 2020; 7: 1725–1734. <https://doi.org/10.1002/nop2.557>
5. Stone, E.M., Bonsignore, S., Crystal, S. and Samples, H. (2025), Disabled Patients' Experiences of Healthcare Services in a Nationally Representative Sample of U.S. Adults. Health Serv Res e14598. <https://doi.org/10.1111/1475-6773.14598>
6. Goering S. 'You Say You're Happy, but...': Contested Quality of Life Judgments in Bioethics and Disability Studies. Bioethical Inquiry. 2008;5(2-3):125-135. doi:10.1007/s11673-007-9076-z
7. Ubel PA, Loewenstein G, Schwarz N, Smith D. Misimagining the unimaginable: the disability paradox and health care decision making. Health Psychology. 2005;24(4S):S57.
8. Iezzoni LI, Rao SR, Ressler J, et al. Physicians' Perceptions Of People With Disability And Their Health Care: Study reports the results of a survey of physicians' perceptions of people with disability. Health Affairs. 2021;40(2):297-306. doi:10.1377/hlthaff.2020.01452
9. Lundberg DJ, Chen JA. Structural ableism in public health and healthcare: a definition and conceptual framework. Lancet Regional Health Americas. 2023 Dec 18;30:100650. doi: 10.1016/j.lana.2023.100650
10. VanPuymbrouck L, Friedman C, Feldner H. Explicit and implicit disability attitudes of healthcare providers. Rehabilitation Psychology. 2020 May;65(2):101-112. doi: 10.1037/rep0000317.
11. Iezzoni LI, Rao SR, Ressler J, Bolcic-Jankovic D, Agarannik ND, Donelan K, Lagu T, Campbell EG. Physicians' Perceptions Of People With Disability And Their Health Care. Health Aff (Millwood). 2021 Feb;40(2):297-306. doi: 10.1377/hlthaff.2020.01452.
12. Moura I. Encoding normative ethics: On algorithmic bias and disability. First Monday. Published online 2023. Accessed July 18, 2024. <https://firstmonday.org/ojs/index.php/fm/article/view/12905>
13. Ne'eman A, Stein MA, Berger ZD, Dorfman D. The treatment of disability under crisis standards of care: an empirical and normative analysis of change over time during COVID-19. Journal of health politics, policy and law. 2021;46(5):831-860.

14. Andrews EE, Ayers KB, Brown KS, Dunn DS, Pilarski CR. No body is expendable: Medical rationing and disability justice during the COVID-19 pandemic. *American Psychologist*. 2021;76(3):451.
15. Landes SD, Finan JM, Turk MA. COVID-19 mortality burden and comorbidity patterns among decedents with and without intellectual and developmental disability in the US. *Disability Health Journal*. 2022 Oct;15(4):101376. doi:10.1016/j.dhjo.2022.101376
16. National Institute of Health. NIH Overview: Populations with Health Disparities. NIH Overview: Populations with Health Disparities. October 3, 2023. <https://www.nimhd.nih.gov/about/overview/>
17. National Health Law Program. HHS Finalizes Rule to Strengthen Protections for People with Disabilities in Health Care. <https://healthlaw.org/news/hhs-finalizes-rule-to-strengthen-protections-for-people-with-disabilities-in-health-care/>
18. Krahn GL, Walker DK, Correa-De-Araujo R. Persons with disabilities as an unrecognized health disparity population. *American Public Health Association*. 2015 Apr;105 Suppl 2(Suppl 2):S198-206. doi: 10.2105/AJPH.2014.302182