MDDC Policy Spotlight: End-of-Life Options

April, 2025

Background

- “End-of-life options” is a big category in healthcare. It includes different ways people can make plans and choices about the end of their life.
- “End-of-life options” include decisions like Advance Care Planning or Advance Care directives.
- These are plans that people make with doctors about the type of care they receive at the end of their life. Some people do not want to receive a lot of medical treatment if they get very sick. They might choose to say “no” to specific treatments like surgery.
- These plans might include “Do Not Resuscitate” (DNR) orders. DNR is when a person is dying because their heart or breathing stops, and they tell healthcare professionals not to save their life.
- End-of-life options also include plans and choices people make about wanting to end their own life with the guidance of healthcare professionals.
- This has been called many different things like voluntary euthanasia, Medical Assistance in Dying (MAiD), Physician-Assisted Suicide (PAS), etc.
- A new bill in Massachusetts uses “End-of-Life Options” in the title (H.2505/S.1486). This bill is about ending one’s own life with the help of a doctor and uses the label “Medical Assistance in Dying” (MAiD).

What is Medical Assistance in Dying?

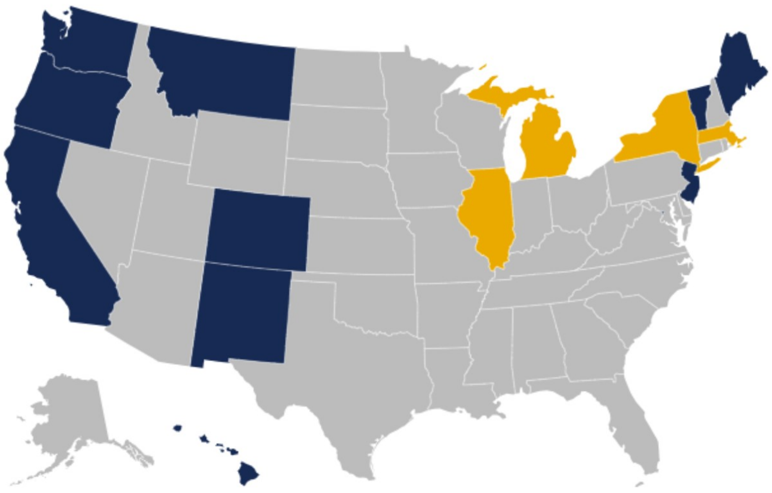
- Medical Assistance in Dying (MAiD) is when a healthcare professional, like a doctor or nurse, helps a person end their own life.[1,2]
- Usually, doctors do this by giving someone a prescription medication. When the person takes this medicine by themselves, they will die.
- This is similar to Physician-Assisted Suicide (PAS). PAS can be different from MAiD if the doctor administers the medicine that ends the person’s life.

MAiD Laws in the United States

- MAiD is not currently legal, or allowed, in Massachusetts.
- MAiD is also not allowed in most states in the United States.
- MAiD is only allowed in 11 states and territories.
- Four more states are considering legalizing MAiD, including Massachusetts.[1]
- 26 states have proposed MAiD laws, but they did not pass. [1]
- There are different rules about MAiD in the states that allow it.
- Overall, people may be eligible for MAiD if they:[1]
  - are an adult and live in the state where it is allowed,
  - have a terminal illness, or a sickness that they will die from in the next 6 months,
  - are able to make the choice themselves,
  - are not pressured to make this choice because of outside influences.
- In Massachusetts, House Bill H.2505 and Senate Bill S.1486 are currently under review in the Joint Committee on Public Health. This proposed law includes additional rules.
  - For example, people who have guardians would not be eligible to use MAiD under this law.
  - People need to request MAiD using spoken and written communication.
  - Some people with disabilities, like people who are Deaf or who do not use these communication forms, would not be allowed to access MAiD.

Status of MAiD in each State [1]

Data provided in 2024



● Allowed

● Under consideration

● Not Allowed

States where MAiD is allowed: California, Colorado, District of Columbia, Hawai'i, Maine, Montana, New Jersey, New Mexico, Oregon, Vermont, and Washington.

States where MAiD is being considered: Illinois, Massachusetts, Minnesota, and New York.

What do disability advocates think about Medical Assistance in Dying?

- People have different opinions about MAiD.
- Some people believe this is a good option for people who have a terminal illness or who are experiencing a lot of pain.
- They believe that MAiD helps people have dignity and self-determination about how they die.
- Other people believe this is a dangerous law, especially for people with disabilities. People with disabilities are not always treated the same as other people in healthcare systems, and some individuals worry that this could happen with MAiD.
- Disability organizations like the National Council on Disabilities, TASH, and The Arc have positions that MAiD laws are dangerous for people with disabilities.[3,4]

How is MAiD related to healthcare?

- MAiD happens in healthcare systems. These systems include places like hospitals. They also include people like doctors and nurses.
- People with disabilities are treated differently in healthcare. Some medical professionals believe that the lives of people with disabilities are not as good or as important as people without disabilities.[5]
- This can result in people with disabilities having less access to the quality healthcare that they need to live.[5]

Examples of how people with disabilities are treated differently in healthcare

- Many doctors do not think the lives of people with disabilities are as good as people without disabilities.[6]
    - However, we know that people with disabilities can live good lives just like anyone else.[7,8] Having a disability does not determine your quality of life.
    - A national survey showed us that 82% of physicians still believe that people with disabilities have a worse quality of life than people without disabilities.[6]
- Only 56% of these physicians believe that their clinics welcome patients with disabilities. [6]
- People with disabilities were treated like they were less important than people without disabilities during early responses to the COVID-19 pandemic.[9]
    - For example, "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 line, and did not get needed care or access to ventilators.[10–12]

Disability and Healthcare: State & Federal Positions

- In recent years, different agencies have made changes to try to protect people with disabilities across healthcare settings.
    - In 2023, the National Institute of Health (NIH) designated people with disabilities as a "health disparity population."[13] This designation intends to provide more resources for research and programs that will help people with disabilities access better healthcare and have better health outcomes.
    - In 2024, the U.S. Department of Health and Human Services announced updates to Section 504 of the Rehabilitation Act. These updates strengthened protections for people with disabilities from being treated differently in healthcare services and programs.[14]
    - In 2025, in Massachusetts, House Bill 1360 and Senate Bill 869 were introduced to help make sure that people with disabilities are treated fairly by doctors and at hospitals. These bills have not passed yet. People with disabilities in Massachusetts are still not protected from being treated differently in healthcare settings.

How do views about disability affect MAiD?

- MAiD is supposed to be a choice that individuals can make.
- People with disabilities may feel more pressure to choose MAiD because they cannot always access treatment they need to be healthy and live comfortably.[3]
- People with disabilities may also feel pressure to choose MAiD because they do not have basic supports and services to live.[3]
- For example, some people in Oregon who accessed MAiD did so because they: [3,15]
    - feel like a burden to their family or friends,
    - do not have enough money to pay for healthcare treatments that can help them live longer,
    - do not have money or support to be comfortable and manage pain.

Do rules about MAiD make it safe?

- MAiD is allowed in some states, like Oregon. It is also allowed in some other countries, like Canada.
- These places have rules or "safeguards" to make sure MAiD is only used in a few, specific cases.
- In these places, we have seen cases when the rules are not followed or become less strict over time. This means people with disabilities may not be protected and may be vulnerable to MAiD.[16]

Some disability advocates say it is more important to help people with disabilities live good lives than to help people with disabilities end their lives.[1]

- For example, many disability advocates are asking lawmakers to pass laws that help people with disabilities live good lives. This includes having budgets and laws that support Home and Community-Based Services (HCBS) and the direct care workforce.[17,18]
- It is important these policy ideas get attention and consideration like proposed MAiD legislation.
- If all people with disabilities do not have access to HCBS or treatment in healthcare settings, it is possible that a law allowing MAiD could have unintended consequences.

Disabled Voices: Harriet McBryde Johnson

- Harriet McBryde Johnson was a famous disability advocate.
- In this quote, she is explaining that people with disabilities do not get to make fair choices when they are not treated the same as people without disabilities.
- She also says people should have support to live good lives before they are offered help with MAiD.

> **"...I argue that choice is illusory in the context of pervasive inequality. Choices are structured by oppression. We shouldn't offer assistance with suicide until we have all the assistance we need to get out of bed in the morning and live a good life." –**
>
> **Harriet McBryde Johnson**

Contacts

- **Jennifer Bertrand, Deputy Director –** Jennifer.Bertrand@mass.gov
- **Joshua Gladstone, Disability Policy Specialist –** Joshua.Gladstone@mass.gov
- **Kaitlin Stober, Policy Research Associate –** Kaitlin.Stober@mass.gov

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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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