Medical Assistance in Dying (MAiD) Report

Kate Caldwell, PhD | Director of Research & Policy

Center for Racial and Disability Justice
Northwestern University Pritzker School of Law

CRDJustice.org

Contents

Dedication 2
Introduction 3
MAiD in the States 4
International Comparisons 7
Ableism & Eugenics 9
Terminology & Definitions 11
Race & Ethnicity 12
Medical Bias 14
Coercion & Safeguard Erosion 15
Normalizing MAiD 18
More Assistance Dying Than Living 19
Undermining Suicide Prevention 21
References 22

Cover: A family of three black or multiracial women, a mother and two daughters, sits on a front porch smiling while holding cups. The sun is casting warm rays on to their faces and two are wearing glasses. They are wearing a variety of clothes, from an athletic hoodie, to a sleeveless knit cardigan, and colorful floral overalls.


Tom Olin

Dedication

> "Legalizing assisted suicide means that some people who say they want to die will receive suicide intervention, while others will receive suicide assistance. The difference between these two groups of people will be their health or disability status, leading to a two-tiered system that results in death to the socially devalued group.
>
> —Diane Coleman

This work is dedicated to the memories of Diane Coleman, JD and Carol Gill, PhD. Carol was a mentor whose sharp, brilliant, compassionate, critical mind had such an influence on me. She always managed to balance challenging us as scholars with nurturing our growth and curiosity. I am the researcher I am today in large part due to her mentorship. In a way, she will always be with us through her work and the impact she has had on people and the field. One such person was Diane herself, who would often speak about her friendship with Carol. Hearing Diane speak about her founding of Not Dead Yet was a pivotal moment in my disability consciousness and informed so much of the work that I do. They both fought so hard for the right to live and for their community. Rest in power.

Kate Caldwell, PhD

Photo by legendary photojournalist Tom Olin of activists sledgehammering the curb: Barbara Waxman, Diane Coleman, Susan Gross, Carol Gill, Steve Remington, Rick Wilson, Yvonne Nau and Bill Bolte. Tom Ollin.

A nurse is monitoring a patient's vital signs while wearing a blue latex glove on her left hand. The nurse and some equipment are visible through a small opening between two blue privacy screens.

Introduction

Throughout the history of euthanasia we see it mired in great sociolegal debates that touch on issues of religious morality, common and criminal law, medicalization and medical ethics, eugenics, prisoner's rights and disability rights. Most infamous among these is the ethnic cleansing of the Nazi party during the Holocaust known as "Aktion T4", an involuntary euthanasia program. This changed the public perception of euthanasia, resulting in not only an entrenchment of laws prohibiting euthanasia, but also of the distinction between voluntary and involuntary euthanasia. Involuntary euthanasia is typically considered a criminal act, except in countries and/or states that permit the death penalty. However, voluntary euthanasia has taken many forms and been referred to by many names, such as "mercy killing", "assisted suicide", and now Medical Assistance in Dying (MAiD).

In most countries euthanasia remains illegal, but the legalization of MAiD has been gaining traction in recent years. Efforts to distance MAiD from euthanasia and physician-assisted suicide (PAS) rest on the claim that the individual, rather than the physician, administers the medication to end their life. Despite this distinction, MAiD remains a form of voluntary euthanasia as it results in the intentional ending of a person's life through medical means. Our Center has spent months parsing through the research and found a wealth of opinion and conjecture passing itself off as fact. This report presents critical research that centers the voices, perspectives, and experiences of disabled people, particularly those who are multiply marginalized, for whom MAiD legislation poses a powerfully coercive force.

MAiD in the States

In the United States (USA), all 50 states prohibit euthanasia. However, MAiD laws have passed in ten jurisdictions: California, Colorado, Hawai'i, Maine, New Jersey, New Mexico, Oregon, Vermont, Washington, District of Columbia and one by legal decision Montana. In 26 states laws were proposed but did not pass. Currently, Bills have been introduced in 4 states (IL, MA, MI, NY). In 9 states MAiD is prohibited, but one of those states recently introduced a Bill (MA). Finally, in two states (DE, NV) the Governor vetoed proposed MAiD legislation. You can find more information in CRDJ's interactive MAiD Toolkit.

A comparison of MAiD legislation across jurisdictions reveals common legal rules with regards to eligibility criteria, informed consent, physician responsibilities, documentation and reporting requirements, legal provisions and regulatory oversight:

Disability rights activist and English actress Liz Carr holding signs in opposition of medical assistance in dying legislation at a Not Dead Yet UK protest. Not Dead Yet UK

Eligibility

An individual must be an adult and a resident of the state where the law is in effect. They should have a terminal illness with a prognosis of six months or less to live. They should have the "mental capacity" to make and communicate health care decisions, and their request should be voluntary (e.g. free from coercion or undue influence). Also, the person must be physically capable of self-administering the aid-in-dying medication.

Informed Consent

Typically, the patient must make multiple requests: at least two oral requests separated by a waiting period and one written request. The written request should be witnessed and often has requirements for who can be a witness. Physicians must properly inform patients about their diagnosis, prognosis, risks attached to the aid-in-dying medication, expected results, and alternatives (e.g. palliative care and hospice). Doctors also have to confirm the patient's decision is voluntary. Patients have to be informed of their right to rescind their consent at any time, and some states have additional required steps for shortly before the patient administers the medicine.

Physician Responsibilities

The attending physician must verify the patient's eligibility and ensure they are making an informed decision. A consulting physician must confirm the diagnosis, prognosis, and the patient's capacity. Physicians must refer patients for mental health evaluations if there are concerns regarding psychological disorders/depression. They must document all requests and relevant information. They are responsible for offering opportunities for the patient to rescind their consent. They should also follow proper protocols for prescribing and providing aid, and they should report cases to the state health department.

Request Process

Generally, patients should make at least two oral requests to their attending physicians, separated by a waiting period that typically lasts 15-20 days. They must also submit a written request, often using a specific form required by the state. The written request should be signed and dated by the patient in the presence of two witnesses. Usually, at least one witness should be unrelated to the patient, not entitled to any portion of their estate, and not employed by the health care facility providing the treatment. Some states require a final attestation form to be completed shortly before taking the medication. Patients must be informed of their right to rescind the request at any time throughout this entire process.

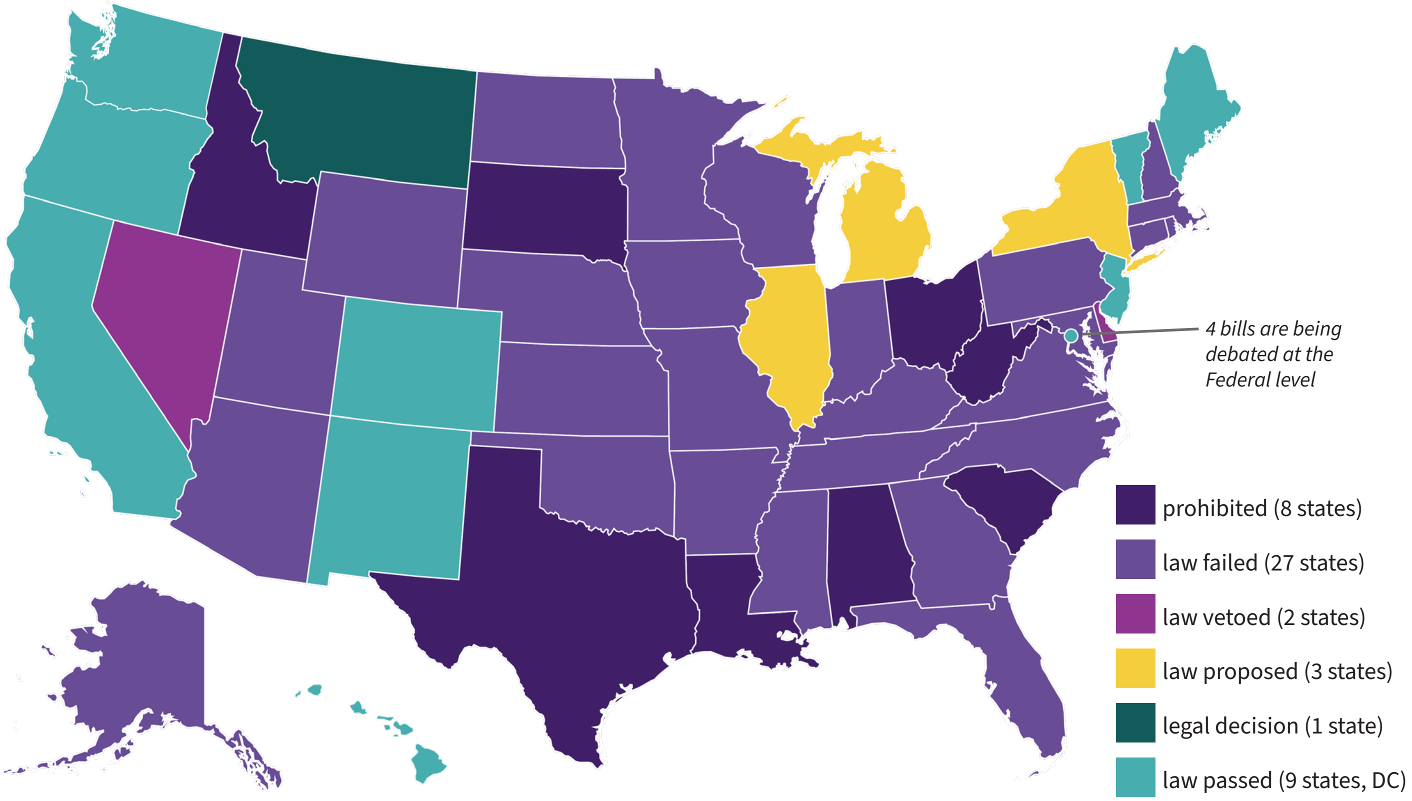
Documentation & Reporting

Physicians should thoroughly document the patient's requests, diagnosis, prognosis, mental capacity assessment, and informed consent process in the medical record. Some specific forms must be completed, like attending physician checklists, consulting physician compliance forms, and the patient's written requests. Most states require physicians to report each case to the state health department, typically within a specific timeframe after writing the prescription or after the patient's death. The physicians must typically collect the patient's demographic data, underlying illness, and whether the patient ingested the medicine. State health departments review this data and produce annual reports excluding personally identifiable information. These reports normally include the number of prescriptions written, the number of known deaths from aid-in-dying medications, and the characteristics of the patients who used the law.

Legal Provisions & Regulatory Oversight

The laws typically provide immunity from civil and criminal liability for health care providers who act in good faith compliance with the law. Health care providers and institutions can voluntarily participate, which gives them the freedom to opt out. The laws specify that actions taken in compliance don't constitute suicide, assisted suicide, mercy killing, or homicide under state law. Most states prohibit life insurance policies from being affected by the patient's choice to use the law. State health departments or medical boards typically oversee the law's implementation, including developing forms, collecting data, and issuing annual reports. Some states have provisions for safely disposing of unused medications. Penalties are typically included for coercing a patient or forging a request.

Current MAiD Legislation in the United States



Further legal analysis of MAiD safeguards reveals similarities and differences between jurisdictions.

SIMILARITIES

- All states require the patient to be an adult resident of the state, capable of making decisions, diagnosed with a terminal illness, and having a prognosis of 6 months or less to live.
- Patients must make multiple requests, including both oral and written requests, with a waiting period between requests.
- Attending physicians must inform patients of their diagnosis, prognosis, risks, probable results, and alternatives.
- Consulting physicians must confirm the patient's diagnosis, prognosis, and capacity to make medical decisions.
- All states have documentation and reporting requirements, typically involving state health departments for oversight.
- Participation is voluntary for both patients and health care providers. Providers can opt-out.
- Immunity from civil/criminal liability and professional discipline is provided for participants acting in good faith compliance.

DIFFERENCES

- Waiting periods between requests vary slightly from 15 to 20 days.
- Witness requirements for written requests differ, with some states requiring one of two witnesses to be unrelated to the patient.
- Some states, like Hawai'i and Maine, require counseling or mental health referral if the provider suspects a psychological disorder impairing judgment.
- The forms and specific data collected by state health departments for annual statistical reports vary.
- Some states, like Colorado and California, require specific final attestation forms shortly before taking the medication.
- A few states, like Hawai'i and Washington, specify that unused medications must be properly disposed of after death.
- Newer laws (e.g., New Mexico) tend to have more detailed language around provider opt-outs and institutional prohibitions on participation.

Fred Dufour/AFP/Getty Images

Protestors dressed as a theatrical mime take part in an anti-euthanasia demonstration in Trocadero plaza. They are holding black and white signs and the Eiffel Tower looms in the distance.

Liz "blue tick" Carr @thelizcarr · 22h

If legalised, assisted suicide will be administered by the NHS

A letter signed by 3,400 healthcare professionals warns that inadequate health & hospice care means assisted suicide cannot be introduced safely while the NHS is broken

Even the best safeguards won't be safe enough

> **Janet Eastham** @JanetEastham · Nov 10
>
> ▲ EXC: Assisted dying cannot be brought in safely while NHS is broken, medics warn.
> A letter signed by more than 3,000 healthcare professionals warns that inadequate NHS and hospice care could coerce patients into ...
> Show more

International Comparisons

Much of the information about MAiD legislation internationally has been promoted by pro-MAiD organizations and lobbying groups. As such, they present what appears to be misleading talking points that lack accuracy and exhibit bias. For this reason, we are currently compiling critical research in this area from the perspective of racial and disability justice. We will make this information and resources available in our MAiD Toolkit.

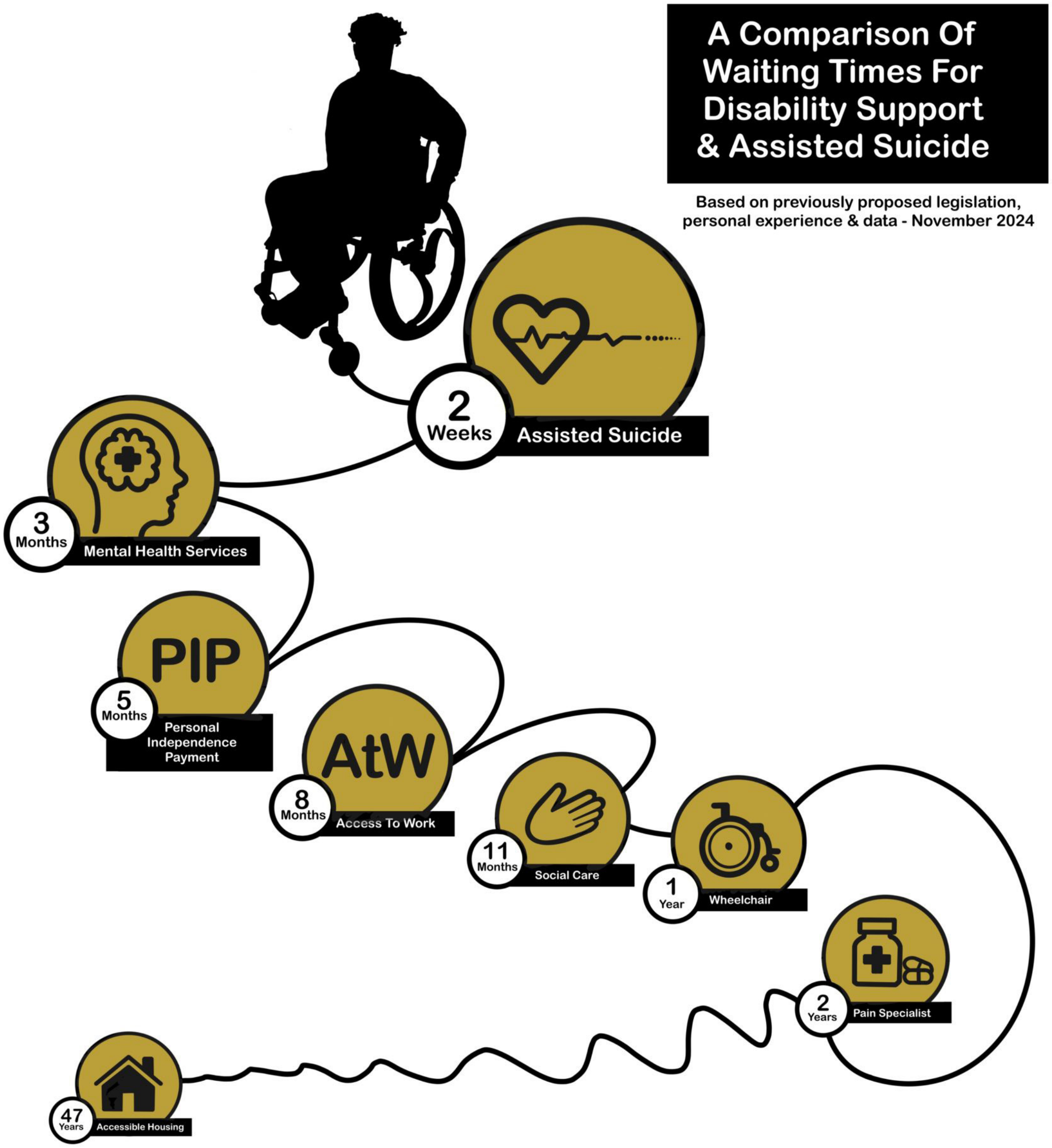
In most countries euthanasia is prohibited, with the exception of Columbia. However, assisted suicide and/or MAiD is permitted in thirteen countries, with some restricting it to certain states or territories. The Netherlands and Belgium are known for having the most permissive policies and experience the phenomenon of "euthanasia tourism." The terminology varies from country to country, as do the legal rules delineated previously. Several countries have seen legislation in this area passed; amended, restricted and/or overturned; and then passed again. There is no clear consensus for or against.

What is clear from the research presented below is that such legislation presents a coercive influence on marginalized populations and that the current safeguards are woefully inadequate.

While the USA has adopted a fragmented approach to MAiD, in 2016 Canada implemented a national policy with broader scope. Canada's implementation has revealed both the potential for expanding access to MAiD and concerns about eroding safeguards, particularly with respect to eligibility criteria, coercion risks, and the normalization of MAiD. These concerns provide valuable lessons for ongoing legal and ethical discussions around MAiD.

A Bill was introduced to Parliament in the United Kingdom (UK) that is currently being hotly contested. The Bill will come to a vote in late November 2024. If it passes it would legalize assisted suicide in England and Wales. This is part of the focus of award-winning actress and disability activist Liz Carr's BBC documentary, Better Off Dead?

The following image comes from a blog written by Jess Thom (2024), a comedian and disability activist in the UK who founded Tourettes Hero. In it, they compare the waiting times that disabled people face for services and supports they need to live in the community versus the waiting time for MAiD – highlighting the stark disparity.



Jess Thom/Tourettes Hero

A diagram of waiting times that people with disabilities usually have to wait for to get supportive services or care uses icons and lines to identify key moments. It is compared to the two-week average window required for assisted suicide.

In Canada and the United Kingdom, legislative proposals and expansions to assisted suicide have sparked demonstrations, many organized by grassroots disability rights organization, *Not Dead Yet.*

A woman holds an anti-MAiD sign pleading doctors for help, not death, at a 2016 protest in Ottawa. Art Babych/CNS

Not Dead Yet UK *Protestors hold red signs urging UK MPs to reject MAiD legislation outside Parliament in London.* The Telegraph

A protester holds an anti-MAiD sign with red-colored latex globes outside Parliament in the UK. Mina Kim/ REUTERS

A handmade sign reads "Mr. Trudeau, do not kill Canadian disabled to balance budget" with a Bible citation underneath. The MAiD critic is a part of a February 2024 rally on Parliament Hill in Ottawa. Susan Korah/CNS

Four protestors wearing white identity-less masks with "euthanasia" written on their foreheads are wearing scrubs and lab coats, holding red signs in opposition of MAiD legislation outisde the British Parliament. Wiktor Szymanowicz/Future Publishing/Getty Images

Ableism & Eugenics

There is a reason why disability rights organizations have universally opposed the legalization of assisted suicide, an opposition shared by allies of disabled people's organizations (DPO), including Black, Indigenous, and people of color (BIPOC) and women's organizations (NCD, 2019; Stainton, 2023). Such legislation, they argue, would institutionalize and legally authorize ableism (Quinn, De Schutter, & Mahler, 2021). The American Medical Association (AMA) also opposes assisted suicide, stating that it "is fundamentally incompatible with the physician's role as healer, would be difficult or impossible to control, and would pose serious societal risks" (Opinion 5.7).

MAiD legislation has been recognized as a human rights violation and condemned by the United Nations (UN) Special Rapporteurs on the Rights of Disabled Persons, the UN Independent Expert on the Enjoyment of all Human Rights by Older Persons, and the UN Special Rapporteur on Extreme Poverty and Human Rights (Coelho, Maher, Gaind, & Lemmens, 2023; Stainton, 2023). According to such UN experts, "disability should never be a ground or justification to end someone's life directly or indirectly" (Frazee, 2024, p. 83). Legal scholars have found MAiD legislation to violate both the right to life and the right to equality under international law, specifically within the Universal Declaration of Human Rights, the International Covenant on Civil and Political Rights, the Convention on the Rights of Persons with Disabilities, and the American Declaration on the Rights and Duties of Man:

> "Contrary to the **right to life** [emphasis added], legislative safeguards have not been effective in protecting persons with disabilities from resorting to MAiD because of suffering related to their systemic civil, social, and economic inequalities. Tragically, the number of documented cases of persons with disabilities resorting to MAiD due to a lack of real alternatives to address their suffering continues to grow. There is a very urgent need to create robust safeguards that actually ameliorate people with disabilities' suffering and provide real, meaningful alternatives to MAiD at the end of life. The introduction of new safeguards cannot, however, remedy the 2021 amendments which allow MAiD for people with disabilities who are suffering but are not at the end of their lives. As we have argued, these amendments violate the **right to equality** [emphasis added] by targeting disability-related suffering for assisted dying, thereby reinforcing negative stereotypes about the value of disabled lives. They are fundamentally discriminatory." (Joffe & Lattanzio, 2023, pp. 364-365)

Critics argue that such legislation is not only poorly conceived, but that its guidelines and practices serve to violate human dignity (Atkins, 2023). Indeed, a review of recent Canadian news media has revealed four main themes that dominate discussions around MAiD: vulnerability, autonomy, dignity, and human rights (Brassolotto, Manduca-Barone, & Zurbrigg, 2023).

Disabled people have a long history of eugenics and euthanasia (Atkins, 2023; Nielsen, 2012). While we tend to think of these as relics of the past, they remain very much alive today, becoming even more prominent during the COVID-19 pandemic. During this time, we saw health care rationing rely upon eugenic thinking with "triage" to determine who deserves access to care, life-saving treatment, and vaccines. This includes reports of do not resuscitate (DNR) orders and advanced care directives being imposed “as a pre-emptive measure to avoid later questions of resource allocation in hospitals” (Chen & McNamara, 2020, p. 513). The increasing acceptance of MAiD legislation (e.g. voluntary euthanasia) alongside the forced imposition of DNRs on disabled people, whose lives are often deemed less worthy of care – should raise significant red flags (Williams, 2022).

We seem to have developed a collective forgetfulness about physician assisted suicide. While the practice has been occurring for centuries, public awareness tends to be cyclical: “‘Each time the issue is rediscovered, the previous history has been forgotten’ (Pernick, April 1997, personal interview)” (Cheyfitz, 2019, p. 8). This historical amnesia allows harmful practices such as euthanasia and assisted suicide to continue and resurge without scrutiny of their past consequences.

Eugenic ideologies never truly went away. Instead, they have remained etched in the collective unconscious, allowing ableism to persist. The quiet resurgence of new eugenics has been linked to policy issues such as pre-natal testing and genetic technology, immigration and the public charge rule, “herd immunity” and the COVID-19 pandemic response (Bagenstos, 2021; Stainton, 2023). Systemic ableism restricts social and economic opportunities for people with disabilities, sometimes to the extent that they feel forced to seek MAiD due to inadequate support for independent living (Janz, 2023). This phenomenon is made even more insidious given that many disabled people may have considered assisted suicide at some point in their lives due to internalized ableism and concerns about being a “burden”, rather than due to their actual preferences (Peters, 2024).

A person is holding a woman’s wrinkled hand, over a blurred depth of field that suggests the older woman is lying down or sitting, wearing a rust-colored blanket.

Terminology & Definitions

The problem of undefined terminology in legislation is extensive (Coelho et al., 2023). For example, the attempt to define "terminal illness" where most definitions fail to account for the influence of physician bias, internalized ableism, and medical racism. To complicate matters, Canada's nation-wide MAiD legislation underwent a constitutional amendment that argued providing MAiD only to the "terminally ill" was discriminatory, and that everyone should have the right to the same "treatment."

> "Following a constitutional challenge, a Quebec lower court, ruled in the Truchon vs. Canada AG case that the restriction to a reasonably foreseeable death is an unjustifiable impingement on the right to life, liberty, and security of the person and the right to equality. In response, the government expanded the MAiD law in March 2021 through Bill C-7 to include those who are not approaching their natural death" (Whitelaw, Lemmens, & Van Spall, 2022, p. 17).

This amendment accomplished two things: First, it created a two-track system for MAiD wherein any disability now qualifies under this expanded definition, along with old age and socioeconomic disadvantage (Brassolotto et al., 2023; Pullman, 2023). There is substantive concern about further expansion of this type of assisted suicide to those with mental illness, particularly depression (Coelho et al., 2023).

> "It is notable in this regard that while only 75% of requests for MAiD in Canada were approved in 2020, 99% were approved in 2021 indicating that assessors are becoming increasingly comfortable with the expanded criteria" (Pullman, 2023, p. 69).

Second, MAiD legislation is intended to end "suffering." However, it is critical to first understand the various ways stigma equates simply living with a disability to "suffering." MAiD can alter public perception, framing disabled lives as not worthy of living, and can exacerbate social and health care discrimination (Brassolotto et al., 2023). Suffering is defined subjectively and can be rooted in psychosocial distress (Coelho et al., 2023). It is not at all clear how physicians minimize their biases, let alone how they are objectively assessing "unbearable suffering" or determining if someone has "no prospect of improving" (Sullivan & Heng, 2023).

> "MAiD assessors afflicted with undiagnosed ableism are likely to automatically view the existence of disability, in and of itself, as the greatest source of suffering. They thus risk conflating suffering stemming from remediable social conditions, such as poverty and the lack of affordable, accessible housing and community-based, user-directed personal support services, with the "irremediable" presence of disability" (Janz, 2023, p. 302).

There has also been confusion around the definition of "reasonably foreseeable" given the extent of physician bias, compounded by centuries of medicalized ableism and racism. Yet, the removal of "reasonably foreseeable" has not lessened confusion and appears to have only exacerbated concerns:

> "Before the House of Commons committee studying Bill C-7, Dr. Heidi Janz testified that, '[t]he removal of 'reasonably foreseeable' natural death as a limiting eligibility criterion for the provision of MAiD will result in people with disabilities seeking MAiD as an ultimate capitulation to a lifetime of ableist oppression'." (Joffe & Lattanzio, 2023, p. 356)

Herb Conaway (D-NJ) has introduced MAiD legislation in New Jersey.
Hal Brown/New Jersey Monitor

An older Black woman wearing a breathing mask looks up at a health care provider wearing blue latex gloves. She is sitting on a yellow couch and is wearing glasses.

Race & Ethnicity

The literature on race and ethnicity when it comes to MAiD is complex and often contradictory. Differences in opinion claim to vary more by spirituality and faith than by race and ethnicity. While this discourse may account for differences in beliefs, it overlooks key issues of vulnerability, particularly for disabled Black, Indigenous, and People of Color (BIPOC).

Marginalized groups experience barriers to accessing MAiD due to implicit bias on the basis of race, gender, class, ethnicity, disability, sexuality, and/or migrant status (Fortin, Lessard, & Samson, 2024; Sikka, 2021). It appears that MAiD is less frequently provided to patients with lower socioeconomic status, showing a 39% decrease under Canada's universal health care system. However, there is a lack of data on the role of race and ethnicity in these disparities (Redelmeier, Ng, Thiruchelvam, & Shafir, 2021). There is also a lack of data on MAiD in Indigenous communities, a perspective that has received little attention (Newman & Robitaille, 2023). This is particularly concerning given that "[p]resenting MAiD as an option for Indigenous patients is viewed by some as a form of neocolonialism" (Brassolotto et al., 2023, p. 175).

Research on end of life experiences of migrants and non-migrants found that unequal access to care is due to several intersecting factors: type of disease, age, uncertainty of the prognosis, and migrant status. Those who did not receive palliative care were more likely to be social minorities and have diseases with an ambiguous prognosis. Indeed, the majority of people who did not receive comfort care were migrants, 36% compared to just 7% of non-migrants. Further, family members who were in favor of MAiD did so because they wanted to see an end to their loved one's suffering, whereas relatives who opposed MAiD cited religious reasons (Fortin et al., 2024).

Overall, MAiD is seen as a threat to the lives of disabled, Indigenous people, and those living in poverty (Brassolotto et al., 2023). It's important to note that people living in poverty are disproportionately BIPOC and/or disabled (Goodman, Morris, & Boston, 2017). Newman and Robitaille (2023) indicate seven key areas of concern specific to, but not limited to, Indigenous communities:

1. **Health care inequities,** including the lack of access to care, leave people vulnerable to coerced consent, whereby someone who would not have previously considered MAiD may seek it due to inadequate and insufficient health and palliative care.

2. Systemic racism, stemming from a history of medical abuse such as forced sterilization, has led to a general distrust of medical services. MAiD can heighten this distrust, thereby reinforcing barriers to health care access and provision.

3. Tension with suicide prevention efforts, particularly because treating mental illness as the sole qualifying condition for MAiD is deeply problematic. Further, there are concerns that young people witnessing MAiD may experience higher rates of suicidality, particularly given how closely health care barriers are tied to the suicide epidemic. MAiD is counterproductive to suicide prevention efforts and sends the message that while some groups receive support to prevent suicide, other, more vulnerable groups, receive suicide assistance.

4. Cultural conscience objections whereby MAiD legislation fails to appreciate cultural and spiritual concerns, not just by individuals under MAiD and their families, but also for various medical and care workers who need workplace protections.

5. Cultural competency concerns include difficulty communicating the concept of MAiD and obtaining truly informed consent, in large part because the understanding of death has cultural differences. Further, the imposition of such legislation may pose a threat to a culture's traditional way of life.

6. Jurisdictional issues that are specific to the provision of services in Indigenous communities need to be addressed before further introduction of MAiD legislation.

7. Inadequate consultation and meaningful engagement with communities affected most by MAiD legislation.

Two women wearing Indigenous folk regalia embrace. The younger woman is smiling while hugging an older woman wearing a bright orange beaded necklace.

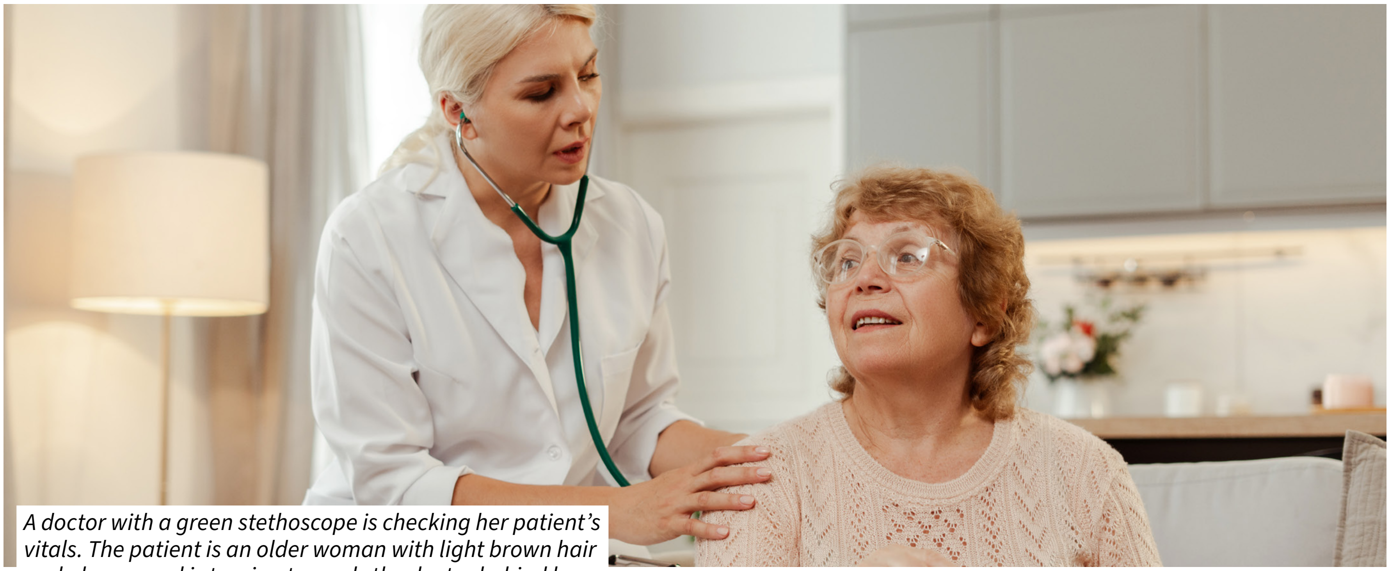
Medical Bias

Simply put, physicians often exhibit bias against people with disabilities and other marginalized identities, frequently conflating disability with suffering (Reynolds, 2017). Bias in health care, including ableism, racism and, (neo)colonialism, results in more negative prognostication and can create fear of seeking medical care (Coelho et al., 2023). Moreover, misdiagnoses of "terminal illness" can cause frightened patients to hasten their deaths, giving into the temptation of having a sense of control over their end of life (Atkins, 2023; NCD, 2019).

However, we know that medical prognostications about end of life and quality of life (QOL) are overly negative and unreliable. Research shows that 82.4% of physicians believe disabled people have a worse QOL (Iezzoni et al., 2021). Physicians are also more pessimistic and upset about prognoses than their patients (Janz, 2023) and tend to rate disabled people's QOL lower than they do for themselves (Peters, 2024). Physicians underestimating QOL leads to a higher risk of exclusion from medical treatments (Janz, 2023). Additionally, people with intellectual and developmental disabilities (I/DD) are often misdiagnosed or given inappropriate treatments and, as a result, do not receive the care and support they need (Sullivan & Heng, 2023). This is due in part to medical professionals' lack of training and experience working with disabled people (Doebrich, Quirici, & Lunsford, 2020; Krahn, Hammond, & Turner, 2006; Krahn, Walker, & Correa-De-Araujo, 2015; Lee, Pollack, Mroz, Frogner, & Skillman, 2023; NCD, 2019).

A persistent element of medical ableism and discrimination is its being deeply rooted in a "eugenic logic" that has been central to medicalization throughout history (Janz, 2023). This logic assumes that disabled people have poor QOL and lives not worth "medical effort or salvage" (Atkins, 2023, p. 102). This can be seen in the utilitarian mindset underlying the medical response to the COVID-19 pandemic (Janz, 2023), which utilized health care rationing tools like the widely criticized quality-adjusted life years (QALYs). QALYs "requires discrimination against the disabled in the allocation of health care resources" to decide whose lives are "worth" saving (Stainton, 2023, p. 314).

MAiD legislation is profoundly problematic because it "relies on health care professionals to act as the sole arbiters of MAiD procedures and implementation, thus prioritizing a medical epistemology" (Atkins, 2023, p. 103), as demonstrated in the CRDJ MAiD Toolkit. Physician involvement can be a powerfully coercive element (Pullman, 2023), particularly as most people are socialized to trust physicians and not challenge their expertise (Rothman, 2003), despite the bias and ableism illustrated here.



A doctor with a green stethoscope is checking her patient's vitals. The patient is an older woman with light brown hair and glasses and is turning towards the doctor behind her.

A protestor in a power chair is holding a sign reading "Assist us to live, not to die" while at a protest organized by Not Dead Yet UK. Several other protestors are around.

Peter Marshall/Alamy

Coercion & Safeguard Erosion

MAiD has been widely criticized for being inherently coercive and exploitative of "vulnerable" populations who are already at higher risk of criminal neglect and abuse (Brassolotto et al., 2023; Braswell, 2022; Gill, 2013; Stainton, 2023). This is especially true for marginalized populations and those whose choices are constrained by prison, poverty, homelessness, racialization, and limited social support services. Constraint itself makes the process inherently coercive, challenging whether autonomy is even possible in a system where coercion is systemic. This is compounded by the financial costs of health care, with people not wanting their families to incur outstanding medical debt due to the cost of their care (Brassolotto et al., 2023). COVID-19 has further increased the vulnerability of disabled people (Brassolotto et al., 2023). According to Whitelaw et al. (2022) the pandemic has heightened disparities, led to more people requesting MAiD, and accelerated MAiD timelines due to COVID-19 restrictions. The increased strain of COVID-19 may also cause vulnerable populations to seek MAiD when they otherwise might not have considered it before.

There has been no meaningful effort to neutralize the power dynamics at play, nor to address the biases inherent in the system – this is the critical issue at the heart of this discussion. The risks of abuse in the MAiD process are high, while safeguards meant to protect citizens are ineffective and insufficient (Coelho et al., 2023; NCD, 2019). This is particularly the case for people with I/DD, who may face unintended or premature death due to a health care system that has not been designed to meet their health and related needs adequately or appropriately (Sullivan & Heng, 2023). Assisted suicide laws have been setting the lowest possible standard of culpability for doctors, medical staff, and other involved parties, requiring only a good-faith belief that the law is being followed, which opens the door to potential abuse (NCD, 2019). Further, there is currently no way of knowing whether or to what extent people are being coerced by medical professionals, family, and/or insurance companies. These financial and emotional pressures can distort patient choice (NCD, 2019) and create a false autonomy of forced choice (Braswell, 2022; Gill, 2013). MAiD often presents a Hobson's choice, which "is defined as a situation in which it seems that you can choose between different things or actions, but there is really only one thing that you can take or do" (Janz, 2023, p. 304), providing an illusion of choice where none truly exists.

Even prior to the expansion of MAiD eligibility in Canada, we saw a dangerously increased loosening of the rules and procedural safeguards in the United States, not only when it comes to eligibility but also in who can prescribe lethal drugs, whether waiting periods are mandatory, and how people with depression are treated (NCD, 2019). What we see happening in Canada is a startling harbinger of things to come. Governments are prioritizing access to MAiD over patient safety and needs, "even when other forms of medical care are available and when psychosocial suffering can be ameliorated" (Coelho et al., 2023, p. 873).

There has been a lack of data collection, oversight, means of investigating mistakes and abuses, and complaint mechanism for the public to report suspected problems (Coelho et al., 2023; NCD, 2019). This is not due to a lack of research, but rather to unnecessarily strict privacy and confidentiality provisions in assisted suicide laws. Current data relies on self-reporting by providers who know not to deviate from the criteria for MAiD under the law. "There is no mechanism for objectively, prospectively, or retroactively identifying or uncovering any errors or abuses of the process" (Coelho et al., 2023, p. 872). Further, the World Health Organization's International Classification of Diseases (ICD) lacks specific coding for tracking data and monitoring global trends related to MAiD and other forms of assisted suicide (Güth, Weitkunat, McMillan, Schneeberger, & Battegay, 2023).

To add fuel to the fire, MAiD in Canada now relies upon an algorithm to assist medical professionals and nurse practitioners with the legal and procedural steps involved (Sullivan & Heng, 2023). However, artificial Intelligence (AI) and algorithms can be biased against people on the basis of their disability, race and ethnicity, potentially exacerbating existing inequities in the health care system. These biases can affect decision-making, further complicating the already fraught process of MAiD. The role of AI in health care decision-making, particularly in the context of MAiD, raises important ethical and fairness concerns, which will be explored in greater detail in our upcoming brief on AI.

Mike Theiler/REUTERS

Outside the United States Supreme Court, Gregory Chant is kneeled in front of protestors while chanting against assisted suicide. He is using mobility devices for support aqnd is wearing a Not Dead Yet orange button on his jacket. Behind him, protestors are holding a large pink banner that is cut off, but also reads "Not Dead Yet" and others are holding raised fists.

Normalizing MAiD

MAiD is increasingly being proactively offered to patients as though it is just one of many standard treatment options; normalizing MAiD as if it is a first-line therapeutic option (Coelho et al., 2023). There are substantial concerns around “steering” or directing disabled people towards MAiD rather than considering alternatives. For instance, unlike some other countries, Canada does not require that all reasonable treatments be tried before MAiD is considered. It has been pointed out that, prior to MAiD legislation, people already had a way to provide control over the end of their lives via advanced directives, such as do not resuscitate (DNR) orders (Brassolotto et al., 2023). Yet, there is no requirement for standard treatments, such as palliative care, to be tried first or even made available. Other countries’ policies (e.g. Belgium and the Netherlands) require physicians to agree that no other options exist that could possibly alleviate “suffering” before MAiD is provided. Some countries, such as New Zealand, have policies that prohibit medical professionals from initiating discussions on MAiD altogether (Coelho et al., 2023). In response to growing concerns, MAiD-free hospitals are beginning to be established as safe spaces for disabled people who don’t want MAiD to be considered part of their care plan; indicating that MAiD is becoming the norm rather than the exception (Peters, 2024). However, this trend raises additional concerns, particularly regarding the religious affiliation of many MAiD-free facilities and the potential stigma surrounding disability and other marginalized identities. In particular, LGBT+ people may feel uncomfortable seeking care at religiously affiliated hospitals due to concerns about potential discrimination or policies influenced by religious beliefs that may not align with their identities or needs.


Compassion and Choices NY

Dr. Sonja Richmond, wearing her monogramed VITAS labcoat, speaks at a podium branded with Compassion and Choices, an organization in support of MAiD legislation for New York.

More Assistance Dying Than Living

When it comes to the reality of MAiD, rather than just an ideological exercise, stories of disabled people have dominated the media and social media. These stories highlight the experiences of people who have been offered assistance in dying more readily than assistance in living (Coelho et al., 2023; Stainton, 2023). This can look like seeking out care/treatment options or services needed to live at home or in the community, only to be denied or placed on lengthy waiting list for years. Meanwhile, they may be sent materials letting them know that they qualify for MAiD. Poverty and lack of financial support have led some to apply for MAiD, even when their death was entirely preventable. For years, disabled people have been using platforms like GoFundMe to help pay for critical services and supports, opting for MAiD to be considered as a last resort. Oftentimes, these individuals do not want to die but cannot see a way to live without the services and support needed. People are opting for MAiD rather than facing the reality of being homeless or living in an institution (NCD, 2019; Stainton, 2023; Whitelaw et al., 2022). However, MAiD is not a solution to the housing and homelessness crisis. Attitudinal barriers and poor health and mental health care experiences can also pressure people to end their life prematurely (Quinn et al., 2021; Whitelaw et al., 2022).

> “One palliative care doctor noted that he can successfully arrange for a medically assisted death for his patients in a more timely and organized process than he can arrange access to mental health care services.” (Brassolotto et al., 2023, p. 175)

Social Determinants of Health (SDOH) are non-medical factors that influence health, such as economic policies and systems, development agendas, social norms, social policies and political systems. For disabled people, SDOH typically includes income and social protection; affordable accessible housing along with community-based, user-directed disability support services; social inclusion and non-discrimination. Disabled people are being pressured to seek MAiD “because systemic ableism caused them to be denied access to the Social Determinants of Health” (Janz, 2023, p. 302). This has a compounding effect on one’s health.

> “In the words of Canadian disability scholar, Jerome Bickenbach, when an individual chooses death as the only viable way to escape an intolerable situation partly brought on by the social environment, it seems ‘perverse and unfair to say that this is an expression of self-determination or autonomy.’” (Bickenbach, 2012, as cited in Janz, 2023, p. 305)

Moreover, research has well established that BIPOC folks are disproportionately impacted by SDOH (Macias-Konstantopoulos et al., 2023). In particular, higher rates of MAiD in Indigenous communities have been linked to limited access to and inequity in: health care, housing, clean water, food and other support services; all of which are further complicated by SDOH (Newman & Robitaille, 2023).

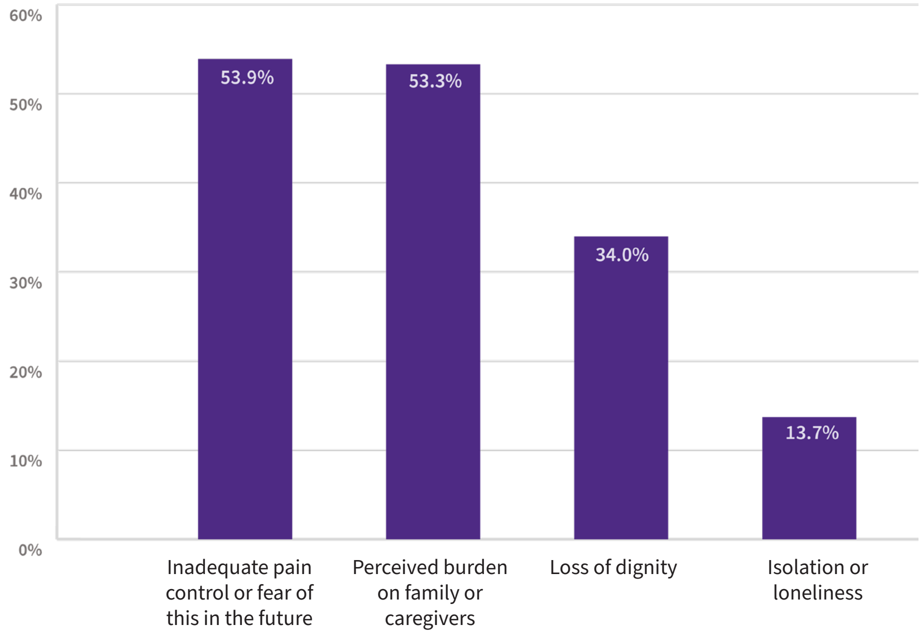
Ultimately, governments and insurers are quicker to provide funding and assistance in dying to disabled people than they are to offer them life-sustaining treatments, services, and supports needed to live in the community. As such, medical decisions are being made based on financial constraints, not based on medical need (Coelho et al., 2023; NCD, 2019; Stainton, 2023). After all, MAiD is a cheaper option than providing quality community services and supports (Brassolotto et al., 2023). This seems painfully ironic given how disability advocates have spent decades challenging the institutional bias by demonstrating that providing services and supports in people’s homes and in the community is cheaper than in institutional settings. The Hobson’s choice being presented here is that, due to the unavailability of community services and supports, disabled people are left with a “choice” between living in an institution, being homeless, or choosing MAiD. This presents an absurdist and dangerous reversion, deeply rooted in medicalization and eugenics, hastening the deaths of disabled people when there are preventative steps that can be taken (NCD, 2019; Stainton, 2023).

MAiD should not be used as an alternative to treatment, pain management, hospice, or palliative care. In fact, one-hundred and seventy scholars, clinicians, and researchers in palliative care and related fields signed a report refuting claims made in the publication, *Medical Assistance in Dying, Palliative Care, Safety, and Structural Vulnerability*, which dismissed structural vulnerability as a concern in MAiD provision (Gallagher et al., 2023). The new report argued that the previous publication withheld critical information, selectively represented data to confirm a point of view, made it nearly impossible to detect and assess excess mortality, and incongruously suggested that palliative care was responsible for unintended deaths. It also raised substantive concerns around biased MAiD data collection and oversight, intending to portray the program positively.

For over a decade, improvements in palliative care have demonstrated potential to reduce requests for assisted suicide (NCD, 2019). Research looking at the most important reasons for requesting MAiD revealed that the leading reason was loss of control and independence, followed by loss of ability to do enjoyable and meaningful activities, illness-related suffering (e.g. pain, nausea, etc.), fear of future suffering, and a previous negative experience around death and dying (Wiebe, Shaw, Green, Trouton, & Kelly, 2018). However, according to the 2019 Health Canada MAiD Annual Report (Whitelaw et al., 2022), the most commonly cited reasons for the "intolerable suffering" that caused them to opt for MAiD included:

Preventable Reasons for "Intolerable Suffering" Leading to MAiD

Based on Whitelaw et al.'s (2022) assessment of the 2019 Health Canada MAiD Annual Report.



Each of the reasons provided are preventable and/or can be addressed effectively through palliative care. When looking at access to services, research found that 10.2% of people who received MAiD did not have access to any disability services and supports at all (Whitelaw et al., 2022). Clearly, there is an urgent need for better access to palliative care. Efforts should be made to provide it along with community-based services and supports before MAiD is considered as an option. Failing to do so effectively treats MAiD as a first-line treatment option, steering disabled people into it.

The criminalization of pain is another significant issue that needs attention. Due to the opioid crisis, people who depend on opioids to manage pain often find themselves treated like criminals. It may become easier to obtain a prescription to die than one to relieve pain (NCD, 2019).

A group of BIPOC individuals wearing facemasks are sititng at an outdoor picnic table. As they talk amongst themselves, they are coloring and doing puzzles.

Undermining Suicide Prevention

The normalization of MAiD undermines suicide prevention efforts, particularly in the communities that need it most. It shifts public perception, fostering the view that disabled lives are not worth living and exacerbates social and health care discrimination (Brassolotto et al., 2023). There is evidence of “suicide contagion” in states where assisted suicide is legal (NCD, 2019). Suicide contagion refers to the phenomenon where the publicizing of suicides, especially when positively portrayed, leads to more people choosing suicide. It contradicts established suicide prevention research and interventions. Much of the media coverage concerning MAiD violates the World Health Organization’s guidelines for responsible reporting on suicide (Peters, 2024). The research simply does not support the argument that providing MAiD reduces rates of (non-assisted) suicide. Rather, it is likely the opposite, but we lack the data to know for sure (Coelho et al., 2023).

Conclusion

The debate surrounding Medical Assistance in Dying (MAiD) legislation is a complex and deeply consequential issue that intersects with questions of ethics, equity, and societal values. This report has highlighted the critical concerns and considerations that must inform discussions about MAiD, particularly as it relates to the most vulnerable populations.

Key findings underscore that while MAiD laws are intended to provide individuals with a sense of autonomy at the end of life, they reveal significant systemic shortcomings. Disabled individuals, people living in poverty, Indigenous and communities of color, and other marginalized groups are disproportionately impacted by structural inequities that often constrain their choices. The troubling reality is that these individuals are more likely to be offered assistance in dying than the supports necessary to live with dignity.

A Muslim family relaxes and smiles in a home living room. An older man sits in a wheelchair pushed by a younger man, while two female relatives sit next to them on a teal sofa.

A mother kneels next to her two daughters as they focus on a yellow Labrador retriever. One daughter is sitting in a red chair, watching her sister feed the dog a treat.

This systemic ableism and economic neglect echo historical patterns of eugenics and undermine the principle that all lives hold equal value.

Moreover, medical bias and the inherent power dynamics between patients and providers raise serious ethical concerns. Physicians often underestimate the quality of life of disabled individuals, leading to recommendations for MAiD that may reflect bias rather than genuine patient autonomy. The lack of robust safeguards, meaningful oversight, and comprehensive data collection further compounds the risks of coercion and abuse. These gaps in accountability and regulation highlight a dangerous erosion of safeguards intended to protect vulnerable populations.

International comparisons, particularly with Canada's expanded MAiD policies, reveal the risks of broadening eligibility criteria without addressing systemic inequities. Canada's experience demonstrates how expanded MAiD access can normalize assisted dying as a solution to social and economic inequalities, rather than addressing the root causes. This normalization also poses significant challenges to suicide prevention efforts, as it reframes death as a socially acceptable response to adversity.

To move forward responsibly, policymakers must prioritize the development of comprehensive programs and policies that address the root causes of social and economic inequality. This includes ensuring access to affordable, accessible housing; community-based disability services; equitable health care; and robust palliative care options. MAiD legislation should not become a substitute for addressing systemic failures. In jurisdictions that already have MAiD legislation, safeguards must be significantly strengthened to mitigate the risks of coercion, bias, and abuse, with particular attention to the perspectives of disabled individuals, Indigenous and communities of color, and other marginalized groups. It has not been proven whether this is, in fact, possible to achieve. If it is not, then MAiD legislation cannot be responsibly implemented. Either way, rigorous data collection and oversight are essential to ensuring accountability and informed policy development. By centering the voices of those most affected and committing to systemic reform, we can work toward a society where every individual is truly empowered to live with dignity.

References

- **Atkins, C. G.** (2023). A Disabled Bioethicist's Critique of Canada's Medical Assistance in Dying (MAID). The American Journal of Bioethics, 23(11), 102-104.
- **Bagenstos, S. R.** (2021). The new eugenics. Syracuse L. Rev., 71, 751.
- **Brassolotto, J., Manduca-Barone, A., & Zurbrigg, P.** (2023). Medical Assistance in Dying: A Review of Related Canadian News Media Texts. Journal of Medical Humanities, 44(2), 167-186.
- **Braswell, H.** (2022). Between "Aid in Dying" and "Assisted Suicide": Disability Bioethics and the Right to Die The Disability Bioethics Reader (pp. 212-220): Routledge.
- **Chen, B., & McNamara, D. M.** (2020). Disability Discrimination, Medical Rationing and COVID-19. Asian Bioeth Rev, 12(4), 511-518. doi:10.1007/s41649-020-00147-x
- **Cheyfitz, K.** (2019). Who decides? The connecting thread of euthanasia, eugenics, and doctor-assisted suicide Right to die versus sacredness of life (pp. 5-16): Routledge.
- **Coelho, R., Maher, J., Gaind, K. S., & Lemmens, T.** (2023). The realities of medical assistance in dying in Canada. Palliative & supportive care, 21(5), 871-878.
- **Doebrich, A., Quirici, M., & Lunsford, C.** (2020). COVID-19 and the need for disability conscious medical education, training, and practice. Journal of pediatric rehabilitation medicine, 13(3), 393-404.
- **Fortin, S., Lessard, S., & Samson, M.-È.** (2024). Diversity and Access to Palliative Care and Medical Assistance in Dying in an Urban Setting. OMEGA-Journal of Death and Dying, 00302228241237834.
- **Frazee, C.** (2024). MAID Resistance in Canada: Sounding the Five-Minute Entreaty. Canadian Journal of Disability Studies, 13(2), 1-175.
- **Gallagher, R., Coelho, R., Violette, P. D., Gaind, K. S., Chochinov, H. M., & Professionals, A. I. C. o. P. C.** (2023). Response to Medical Assistance in Dying, Palliative Care, Safety, and Structural Vulnerability. Journal of Palliative Medicine, 26(12), 1610-1617.
- **Gill, C. J.** (2013). The false autonomy of forced choice: Rationalizing suicide for persons with disabilities Contemporary perspectives on rational suicide (pp. 171-180): Routledge.
- **Goodman, N., Morris, M., & Boston, K.** (2017). Financial inequality: disability, race and poverty in America. National Disability Institute.
- **Güth, U., Weitkunat, R., McMillan, S., Schneeberger, A. R., & Battegay, E.** (2023). When the cause of death does not exist: time for the WHO to close the ICD classification gap for Medical Aid in Dying. EClinicalMedicine, 65.
- **Iezzoni, L. I., Rao, S. R., Ressalam, J., Bolcic-Jankovic, D., Agaronnik, N. D., Donelan, K., . . . Campbell, E. G.** (2021). 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, 40(2), 297-306.
- **Janz, H.** (2023). MAID to die by medical and systemic ableism Medical assistance in dying (MAID) in Canada: Key multidisciplinary perspectives (pp. 299-308): Springer.
- **Joffe, K., & Lattanzio, R.** (2023). Canada's Medical Assistance in Dying Law and the Rights to Life and Equality at International Law Medical Assistance in Dying (MAID) in Canada: Key Multidisciplinary Perspectives (pp. 355-369): Springer.
- **Krahn, G. L., Hammond, L., & Turner, A.** (2006). A Cascade of Disparities: Health and Health Care Access for People with Intellectual Disabilities. Mental Retardation and Developmental Disabilities Research Reviews, 12(1), 70-82. doi:10.1002/mrdd.20098
- **Krahn, G. L., Walker, D. K., & Correa-De-Araujo, R.** (2015). Persons With Disabilities as an Unrecognized Health Disparity Population. American Journal of

Public Health, 105(Suppl 2), S198-S206. doi:10.2105/AJPH.2014.302182

- **Lee, D., Pollack, S. W., Mroz, T., Frogner, B. K., & Skillman, S. M.** (2023). Disability competency training in medical education. Medical Education Online, 28(1), 2207773.
- **Macias-Konstantopoulos, W. L., Collins, K. A., Diaz, R., Duber, H. C., Edwards, C. D., Hsu, A. P., . . . Sachs, C. J.** (2023). Race, healthcare, and health disparities: A critical review and recommendations for advancing health equity. Western journal of emergency medicine, 24(5), 906.
- **NCD.** (2019). The Danger of Assisted Suicide Laws. Retrieved from Washington DC: https://www.ncd.gov/report/the-danger-of-assisted-suicide-laws/
- **Newman, D., & Robitaille, G.** (2023). Examining Indigenous Perspectives on Medical Assistance in Dying (MAID) Medical Assistance in Dying (MAID) in Canada: Key Multidisciplinary Perspectives (pp. 373-384): Springer.
- **Nielsen, K. E.** (2012). A Disability History of the United States. Boston, MA: Beacon Press.
- **Peters, G.** (2024). Reality, not religion, is the reason people need MAiD-free health care. Policy Options. Retrieved from https://policyoptions.irpp.org/magazines/april-2024/maid-free-health-care/
- **Pullman, D.** (2023). Slowing the Slide Down the Slippery Slope of Medical Assistance in Dying: Mutual Learnings for Canada and the US. The American Journal of Bioethics, 1-9.
- **Quinn, G., De Schutter, O., & Mahler, C.** (2021). Disability is not a reason to sanction medically assisted dying – UN experts [Press release]. Retrieved from https://www.ohchr.org/en/press-releases/2021/01/disability-not-reason-sanction-medically-assisted-dying-un-experts
- **Redelmeier, D. A., Ng, K., Thiruchelvam, D., & Shafir, E.** (2021). Association of socioeconomic status with medical assistance in dying: a case–control analysis. BMJ open, 11(5), e043547.
- **Reynolds, J. M.** (2017). "I'd rather be dead than disabled"—the ableist conflation and the meanings of disability. Review of Communication, 17(3), 149-163. doi:10.1080/15358593.2017.1331255
- **Rothman, D. J.** (2003). Strangers At the Bedside: A History of How Law and Bioethics Transformed Medical Decision Making (2nd pbk. ed.). New York, NY: Aldine de Gruyter.
- **Sikka, T.** (2021). Barriers to access: A feminist analysis of medically assisted dying and the experience of marginalized groups. OMEGA-Journal of Death and Dying, 84(1), 4-27.
- **Stainton, T.** (2023). Assisted Life Before Assisted Death: Disability Discomfort Regarding MAID Medical Assistance in Dying (MAID) in Canada: Key Multidisciplinary Perspectives (pp. 309-323): Springer.
- **Sullivan, W. F., & Heng, J.** (2023). Implementing Medical Assistance in Dying in Canada: Implications for People with Intellectual and Developmental Disabilities Medical Assistance in Dying (MAID) in Canada: Key Multidisciplinary Perspectives (pp. 325-338): Springer.
- **Thom, J.** (2024). No Time To Die. Retrieved from https://www.touretteshero.com/2024/10/29/no-time-to-die/
- **Whitelaw, S., Lemmens, T., & Van Spall, H. G.** (2022). The expansion of medical assistance in dying in the COVID-19 pandemic era and beyond: Implications for vulnerable Canadians. Canadian Journal of General Internal Medicine, 17(2), 17-21.
- **Wiebe, E., Shaw, J., Green, S., Trouton, K., & Kelly, M.** (2018). Reasons for requesting medical assistance in dying. Canadian Family Physician, 64(9), 674-679.
- **Williams, R. M.** (2022). "Only the Old and Sick Will Die"-Reproducing 'Eugenic Visuality'in COVID-19 Data Visualization. Paper presented at the 2022 IEEE International Symposium on Technology and Society (ISTAS).

CENTER FOR
RACIAL & DISABILITY
JUSTICE