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**Submission of British Columbia Aboriginal Network on Disability Society, Council of Canadians with Disabilities, DisAbled Women’s Network Canada, Inclusion Canada, and Vulnerable Persons Standard to the Human Rights Committee**

On the List of Issues Prior to Reporting for Canada to be adopted during the 132nd Session of the Human Rights Committee (28 June to 23 July 2021)

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# About this Submission

The focus of this submission is on medical assistance in dying (MAiD) legislation in Canada, its grave consequences and its deeply discriminatory impact on persons with disabilities. In Canada, MAiD includes the administration of medication that will cause a person’s death at their request and the prescription or provision of medication that a person can self-administer to cause their own death.[[1]](#footnote-1)

The British Columbia Aboriginal Network on Disability Society, the Council of Canadians with Disabilities, the DisAbled Women’s Network Canada, Inclusion Canada, and the Vulnerable Persons Standard jointly make this submission to provide the Human Rights Committee with information about the implications of MAiD for Canada’s compliance with the *International Covenant on Civil and Political Rights* (ICCPR),[[2]](#footnote-2) and to urge the Committee to include questions about MAiD in the List of Issues Prior to Reporting for Canada.

The **British Columbia Aboriginal Network on Disability Society (BCANDS)** is an award-winning, Indigenous not for profit society serving the unique and diverse disability and health resource and support service needs of Indigenous peoples across Canada. BCANDS has successfully delivered Indigenous disability and health programs and services across Canada for 30 years. More information is available at: [www.bcands.bc.ca](http://www.bcands.bc.ca)

The **Council of Canadians with Disabilities (CCD)** is a national human rights organization of people with disabilities working for an inclusive and accessible Canada. CCD has members from almost all provinces and territories in Canada. Its members are national, provincial and territorial cross-disability, consumer-controlled, human rights organizations. More information is available at: [www.ccdonline.ca](http://www.ccdonline.ca)

The **DisAbled Women’s Network Canada (DAWN-RAFH)** works toward the advancement and inclusion of women and girls with disabilities and Deaf women in Canada. It’s mission is to end the poverty, isolation, discrimination and violence experienced by women with disabilities and Deaf women. More information is available at: <https://www.dawncanada.net/>

**Inclusion Canada,** formerly the Canadian Association for Community Living, is a national federation of 13 provincial-territorial associations and over 300 local associations working to advance the full inclusion and human rights of people with intellectual disabilities and their families in Canada. More information is available at: <https://inclusioncanada.ca/>

The **Vulnerable Persons Standard** **(VPS)** was created by over 50 disability rights, legal, ethics and medical experts to support and assist policy-makers now working to regulate the practice of medical assistance in dying. The Standard incorporates five evidence-based safeguards intended to protect the lives of Canadians and ensure that MAiD does not jeopardize the lives of persons who because of their personal characteristics, circumstances or social position may be vulnerable to abuse, coercion, undue pressure and inducement to suicide. More information is available at: [www.vps-npv.ca](http://www.vps-npv.ca)

In addition, the following disabled persons organizations and civil society organizations support this submission:

* Canadian Association of the Deaf (CAD-ASC)
* Disability Justice Network of Ontario (DJNO)
* Institute for Research and Development on Inclusion and Society (IRIS)
* National Network for Mental Health (NNMH)
* Dignity Denied
* Independent Living Canada
* Citizens with Disabilities – Ontario (CWDO)
* People First of Canada
* Disability Rights Coalition of Nova Scotia
* Toujours Vivant-Not Dead yet
* Open Access Foundation for Arts and Culture
* L’Arche Canada
* Canadian Institute for Inclusion and Citizenship, University of British Columbia
* Inclusive Design Research Centre, OCAD University

# About Medical Assistance in Dying Legislation in Canada

MAiD was first legalized in Canada in 2016, when the Government of Canada amended Canada’s *Criminal Code* to allow for MAiD in limited circumstances. These amendments responded to a Supreme Court of Canada decision that struck down the prohibition on assisted suicide in the Canadian *Criminal Code*.[[3]](#footnote-3) According to this decision, the *Criminal Code* prohibition created a deprivation of the right to life, liberty and security of person not in accordance with fundamental justice under the *Canadian Charter of Rights and Freedoms* (*Canadian Charter*) because it prevented people who could clearly consent to MAiD from obtaining it when they had a “grievous and irremediable medical condition [...] that causes enduring suffering that is intolerable to the individual”.[[4]](#footnote-4) The case was brought by applicants who were at the end of life, and the decision was made in that context.

The 2016 amendments provide a legal exception to the prohibition on assisted suicide that still stands in the *Criminal Code*. They permit physicians and nurse practitioners to provide MAiD and pharmacists, family members or other people to assist in the process in strictly defined conditions, without facing criminal charges. Under this law, the provision of MAiD was permitted only for persons who had a grievous and irremediable medical condition (including a serious and incurable illness, disease or disability) that caused enduring and intolerable suffering; and whose death was reasonably foreseeable.[[5]](#footnote-5)

Practically, this meant that only persons with serious illnesses or disabilities who were approaching death were permitted to receive MAiD. Persons with or without disabilities whose death was not reasonably foreseeable could not receive MAiD. Limiting MAiD to people who were on a clear trajectory toward death was an important safeguard, understood as an absolute minimum level of protection, included in the legislation to prevent the premature death of persons who might have years to live. Disability rights advocates characterized this safeguard as preserving “...fundamental principles of equality by recognizing disability as a characteristic that is relevant but not determinative of MAiD eligibility.”[[6]](#footnote-6)

Nonetheless, scholars, advocates and other experts in human rights and disability justice have raised persistent alarms over the last five years on the basis that death by MAiD was becoming, for people with disabilities, an expedient ‘solution’ to pervasive problems of social neglect, material deprivation, forced institutionalization, and the natural despair to which these conditions give rise.

In 2019, the Superior Court of Québec held that the 2016 MAiD law violated the *Canadian Charter* and Quebec’s *Act Respecting End-of-Life Care.*[[7]](#footnote-7) The Court found that restricting MAiD to persons whose death was reasonably foreseeable violated the right to equality and the protection against deprivations of life, liberty and security of the person in Canadian law that are not consistent with the principles of fundamental justice.

The Superior Court of Québec is a trial court in one province of Canada, and therefore its ruling applied only to that province. It is rare for a government not to defend its own legislation that has been found to be unconstitutional. This refusal is particularly notable given that the very same government had introduced and passed this legislation just four years earlier. However, instead of subjecting the ruling to the scrutiny of a higher court and ultimately the Supreme Court of Canada, the Government of Canada introduced legislation which was ultimately adopted by Parliament in March 2021. This new law amends the 2016 MAiD legislation and significantly expands eligibility for MAiD. Under these amendments, medical assistance in dying is no longer strictly a way to ease people into a less painful death (as it was under the 2016 MAiD legislation), but now is also a state-authorized response to the suffering of persons with disabilities who are not at the end of life.

With the 2021 amendments, MAiD is now permitted for persons whose death is reasonably foreseeable and for persons who are not near the end of their natural life and who meet the eligibility criteria. For both categories, certain threshold requirements must be met - for example, the person must be 18 years old or older,[[8]](#footnote-8) and must have made the request voluntarily.[[9]](#footnote-9) The person must also be provided with information about ways to alleviate suffering, give informed consent, make a written request that is signed, dated, witnessed, and supported by an opinion of a second independent medical practitioner, and must receive an opportunity to withdraw their request.[[10]](#footnote-10) Where death is not reasonably foreseeable, additional requirements must be met: consulting with a third independent practitioner if needed; informing the person of available medical and disability services and supports and offering consultations with service providers; ensuring that available means to relieve suffering are discussed and considered; and providing a waiting period of 90 days.[[11]](#footnote-11) Notably, the 2021 amendments further expand MAiD to people whose only underlying condition is a mental health disability, beginning in March 2023.[[12]](#footnote-12) Appendix 1 provides a more detailed description of the legislation.

Many disabled persons organizations, advocacy organizations, individuals with disabilities, legal experts, and health care experts in Canada have expressed serious concerns about the expansion of MAiD, the discriminatory impact this expansion will have on persons with disabilities, and the grave consequences at stake. UN officials, including the Committee on the Rights of Persons with Disabilities[[13]](#footnote-13), and the former and current Special Rapporteurs on the Rights of Persons with Disabilities[[14]](#footnote-14) have conveyed similar concerns to Canada. In February 2021, a Joint Communication was issued by the UN Special Rapporteur on the Rights of Persons with Disabilities, the Independent Expert on the Enjoyment of all Human Rights by Older Persons, and the Special Rapporteur on Extreme Poverty and Human Rights[[15]](#footnote-15) to the Canadian government in response to the draft legislation expanding access to MAiD based on disability and not end of life. The Joint Communication made a very strong case that the legislation under consideration was discriminatory.

This expansion of MAiD legislation to persons who are not near death raises the stakes exponentially for people with disabilities in Canada, whose grasp on the social determinants of health is precarious, and who may now seek death as their only alternative to intolerable civil, social and economic conditions of life. Moreover, as this practice becomes increasingly normalized and with no independent and effective oversight, experts warn of catastrophic impacts on the dignity and human rights of disabled persons in Canada. In effect, removing the end-of-life requirement in the legislation allows for disability-related suffering to become a legitimate reason to end a person’s life. As this submission will demonstrate, the consequences of such a radical reformulation of the Canadian social contract, especially in the context of existing social and structural inequities that profoundly disadvantage Canadians with disabilities, will be far-reaching and for the most part, irreversible.

Below we describe the grave and discriminatory impacts of Canada’s current MAiD legislation on people with disabilities and the implications for Canada’s compliance with its international obligations under the ICCPR. Since all UN human rights treaties are part of a holistic system, we describe the relationship between relevant rights contained in the *Convention on the Rights of Persons with Disabilities* (CRPD)[[16]](#footnote-16) and the ICCPR. This approach is in keeping with the well accepted principle that the CRPD “...complements the core UN human rights conventions, as it tailors the relevant norms of existing core human rights conventions to the circumstances of persons with disabilities.”[[17]](#footnote-17)

This submission presents the legislative history and social context for medical assistance in dying in Canada, elaborating on the above concerns through the lens of human rights and inclusion. It situates the current law in its Canadian social context, detailing its grave implications both in terms of individual human rights violations, and at the broader societal level where the ableist logic of the law’s most recent formulation both entrenches and perpetuates disability prejudice. It is organized around four principal themes, each of which concludes with recommended questions for the Committee’s LOIPR.

# Persons with Disabilities are being Pressured, Coerced or Induced to Receive MAiD

In Canada, many persons with disabilities are at grave risk of being pressured, coerced or induced to receive MAiD - not because they want to die but because they do not have effective access to the services, supports, social conditions and resources necessary to live dignified lives in the community.

Deplorably, these are not theoretical concerns. In 2019, former Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas Aguilar, reported that she had received information about persons with disabilities in institutions being persuaded to seek MAiD and of medical practitioners not formally reporting cases involving persons with disabilities.[[18]](#footnote-18) During her country visit to Canada, persons with disabilities told her they were offered the illusory “choice” between living in a nursing home and MAiD.[[19]](#footnote-19)

Since MAiD legislation was introduced in Canada, there have been a number of documented cases of persons with disabilities being pressured, coerced or induced to receive MAiD because of a lack of viable alternatives.[[20]](#footnote-20) For example, Archie Rolland, who was diagnosed with ALS or Lou Gehrig’s disease, requested and received MAiD after being transferred against his will from highly specialized care to a geriatric long-term care facility.[[21]](#footnote-21) In his new home, he did not have staff who could communicate with him and provide the essential care he needed. After documenting his sustained efforts at advocacy, he eventually requested MAiD. He said, “it wasn’t the illness that was killing [him]. [He was] tired of fighting for compassionate care.”[[22]](#footnote-22) Similarly, Sean Tagert requested and received MAiD after he was told that he would have to move to a residential care facility far from home because he could not afford the 24-hour care he required at home.[[23]](#footnote-23) Moving would have required him to leave much of his essential communication technology behind and surrender the life-affirming pleasures of time spent with his young son.[[24]](#footnote-24) After fighting for home care for years, Sean Tagert requested MAiD, describing the funding decisions and institutional offerings available to him as “a death sentence.”[[25]](#footnote-25) More cases like Archie’s and Sean’s have been documented in which persons with disabilities experiencing extreme poverty, food insecurity, inadequate housing, inadequate and prohibitively expensive medical care have considered, been pressured or requested to die by suicide or MAiD. Significantly, one of the plaintiffs in the court case that successfully challenged the requirement of reasonably foreseeable natural death, Jean Truchon, expressed a similar sentiment to Sean Tagert and Archie Rolland. In a statement made at a press conference announcing his court challenge, Mr. Truchon declared "(a) life in institutions is not for me."[[26]](#footnote-26)

These accounts are consistent with Canadian academic literature. For example, a recent study demonstrates that persons with disabilities are more likely to report suicidal ideation in part because of greater economic hardship, food insecurity, and a lesser sense of belonging in the community.[[27]](#footnote-27)

## Civil, Social and Economic Inequality Experienced by Persons with Disabilities in Canada

To understand how persons with disabilities are pressured, coerced and induced to receive MAiD, it is critical to consider the civil, social and economic context in which persons with disabilities live. In Canada, persons with disabilities are more likely to experience poverty, inadequate housing or homelessness, unmet healthcare needs, and ableist barriers that prevent them from living lives of dignity and human flourishing. Persons with disabilities who are further marginalized by their racialized, Indigenous, gender, sexual orientation or other identity status may be less likely to be able to access appropriate services and supports, thus compounding their vulnerability to being subtly or overtly pressured to receive MAiD.

Persons with disabilities are more likely to experience poverty as compared to Canadians without disabilities. The Canadian Survey on Disability conducted in 2017 demonstrated that persons with disabilities between the ages of 25 to 64 years were less likely to be employed (59%) as compared to those without disabilities (80%).[[28]](#footnote-28) Similarly, persons with disabilities had a lower median after-tax income as compared to persons without disabilities.[[29]](#footnote-29) In particular, the income of persons categorized as having “severe disabilities” was half that of persons without disabilities.[[30]](#footnote-30) These findings are consistent with the 2014 Longitudinal and International Study of Adults, which demonstrated that 23% of adults with a disability in Canada between 25 to 64 were low income, as compared to 9% of adults without a disability.[[31]](#footnote-31)

Persons with disabilities are also disproportionately affected by homelessness and precarious housing. Estimates suggest that as many as 45% of the overall homeless population in Canada have physical or psychosocial disabilities.[[32]](#footnote-32) In particular, 46% of women who reported being homeless also have a disability.[[33]](#footnote-33) Overall, 17% of people with disabilities in Canada live in households that are in core housing need, with people with disabilities living alone (36%) and in lone parent households (32%) experiencing even higher rates.[[34]](#footnote-34)

Moreover, persons with disabilities experience long wait times for affordable accessible housing and some people - especially those labelled with intellectual disabilities, psychosocial disabilities, or cognitive disabilities - are frequently housed in institutions rather than in the community.[[35]](#footnote-35) In Nova Scotia for example, people with disabilities have been on the waitlist for community based residential services for nearly 20 years,[[36]](#footnote-36) and in the most dire situations, people have been held in psychiatric facilities as they wait.[[37]](#footnote-37) In Ontario, it is common practice for people with intellectual and developmental disabilities to be added to a waitlist for supportive housing as soon as they turn 18, knowing that they will likely be waiting for decades.[[38]](#footnote-38)

Although Canada’s single-payer, publicly administered healthcare system provides basic “core services” free of charge, some essential out-patient treatments and services, including drug therapies, home care, communication/mobility technologies, and some community supports are paid out-of-pocket or by private insurers.[[39]](#footnote-39) People with disabilities without independent financial means therefore find their options for living so severely constrained that they are often forced to surrender a large measure of dignity and autonomy in order to secure needed care in state-managed residential facilities.

Poor conditions in institutions have been reported as a factor that contributes to people with disabilities suffering and seeking MAiD. In a Facebook post written in August 2020, Jennifer Turton-Molgat wrote: “My mom, the most positive, resilient, loving person I know has requested an assisted suicide. She wants to end her life, not because she is in pain or intolerable discomfort, but because she is being held prisoner in her long-term care home and has lost her will to live.”[[40]](#footnote-40) Prior to COVID-19, Raymond Bourbounnais died by MAiD after experiencing a “constant degradation of services” in a nursing home, wanting to “to forget this bad part of my life”.[[41]](#footnote-41) Meanwhile, Arleen Reinsborough expressed a wish to apply for MAiD to avoid having to go to a long-term care home.[[42]](#footnote-42) Institutional living is particularly concerning, since the COVID-19 pandemic has exposed shocking conditions in long-term care homes in some Canadian provinces such as Ontario.[[43]](#footnote-43)

Speaking of life in an institution, Jonathan Marchand told the Canadian Senate:

This place is a medical prison. You no longer have choice and control over your life. Your love life? It’s over. You can’t live with your partner. Your private life? Forget it. A record is kept on your every move. You are now the property of the government. Now it is managers, civil servants, nurses and others who will decide how you will live. You are too independent for their taste? They will break you. You have to submit to their rules. You have to be a good, kind, obedient, grateful little cripple.[[44]](#footnote-44)

Persons with disabilities in Canada also encounter ableist structures and practices in health services. Former Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas Aguilar, observed that the Canadian health care system incorporates systemic ableism that denies needed supports and undermines quality of life for disabled persons.[[45]](#footnote-45) During the COVID-19 pandemic, for example, this ableism has manifested in policies that discriminate against persons with disabilities by deprioritizing persons with disabilities for acute medical care as a triage strategy.[[46]](#footnote-46)

In Canada, persons with disabilities are more likely than nondisabled persons to have unmet health care needs.[[47]](#footnote-47) Structural limitations of Canada’s health care system are more likely than personal reasons to be the cause of these unmet health care needs.[[48]](#footnote-48) For example, persons labelled with intellectual disabilities face barriers because their mental health experiences are mis-attributed or they are told that there is no expertise to provide appropriate care for them.[[49]](#footnote-49) As well, certain medical treatments may not be available in all parts of the country. For example, some people who need lung transplants in Atlantic Canada are required to move to Ontario for months, at their own personal expense, to receive this treatment.[[50]](#footnote-50) Persons with disabilities also experience significant delays in receiving disability and health care services.[[51]](#footnote-51)

Some of these barriers reflect intersectional discrimination. For example, women with disabilities experience discrimination in health care when their self-reported pain is minimized, they are not given enough time to communicate, or they are provided with limited treatment options.[[52]](#footnote-52)

LGBTQI2S persons with disabilities also experience barriers to accessing health care, as they may be stigmatized and their health issues may be ignored because of attitudes about their sexual orientation or gender identity.[[53]](#footnote-53) In a recent Canadian study, trans and non-binary respondents reported a variety of disability identities.[[54]](#footnote-54) 45% of study respondents reported unmet health needs in the last year and 12% reported that they avoided seeking emergency room care because of their trans or non-binary identity.[[55]](#footnote-55)

Data capturing the health outcomes of racialized people in the Canadian healthcare system is lacking, with studies of racialized people with disabilities being particularly sparse[[56]](#footnote-56). Anti-Black racism, in the form of stereotypes, provider bias or lack of awareness has been reported by those interacting with the healthcare system.[[57]](#footnote-57) For example, a 2009 study of family physicians in Nova Scotia found that nearly half of the physicians interviewed denied that race was of social importance to their practice.[[58]](#footnote-58) Racialized people in Canada have lower levels of trust in the medical system,[[59]](#footnote-59) higher rates of mental illness,[[60]](#footnote-60) and self-identify as “unhealthy” at alarmingly high rates.[[61]](#footnote-61) Most recently, the COVID-19 pandemic has shone a light on structural inequalities affecting Black and racialized communities in Canada, which have had higher than average rates of COVID-19 infection and poorer overall health outcomes.[[62]](#footnote-62) In this context, the few Black people with disabilities invited to testify before Canada’s Senate regarding MAiD called the now-current legislation “anti-black and anti-working class” and warned that the law may be “stigma-inducing.”[[63]](#footnote-63)

Indigenous persons with disabilities experience racism and ableism in health care services.[[64]](#footnote-64) For example, they may receive poorer quality of care because they are labelled with stereotypes that they are less “worthy” of care, are intoxicated or drug-seeking, are “frequent flyers” who abuse the healthcare system, are “irresponsible” or unwilling to follow aftercare instructions.[[65]](#footnote-65) This could mean that they are not treated with respect, not believed, do not receive effective communication, experience longer wait times, are subject to mistakes and misdiagnoses, or are denied health care services completely.[[66]](#footnote-66) There is also a high rate of suicide in Indigenous communities attributed to inequalities in these communities and the devastating impacts of colonialism.[[67]](#footnote-67) For example, a recent study reports that between 2015 and 2019, over 100 Indigenous women from 6 provinces and two territories were coerced to undergo a sterilization procedure.[[68]](#footnote-68) During Parliamentary hearings on MAiD legislation, Indigenous participants who testified before Canada’s Senate expressed concern regarding the current MAiD legislation, referring to the health inequalities experienced by their communities.[[69]](#footnote-69)

The civil, social and economic inequality in which persons with disabilities live in Canada contributes to the very real and grave risk that they will be subtly or overtly coerced, pressured or induced to receive MAiD. Within this context, MAiD is being provided to people whose suffering can be alleviated through other measures, such as the provision of timely affordable accessible housing, health care, income supports and disability services and supports. These forms of suffering are demonstrably preventable in Canada and should not be embraced as justifications for MAiD.

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# Contrary to Article 6, Canada’s MAiD Regime Fails to Safeguard Persons with Disabilities from Pressure, Coercion or Inducement to Receive MAiD

As detailed above, cases involving persons whose death was reasonably foreseeable but who appear to have requested MAiD out of desperation arising from their social circumstances, rather than their medical conditions, demonstrate that Canada has failed to implement adequate safeguards to ensure compliance with Article 6 of the ICCPR.

Under Article 6, this Committee has recognized the rights of persons with disabilities to “the effective enjoyment of the right to life on an equal basis with others.”[[70]](#footnote-70) States are required to provide “measures of protection” to guarantee this right, including “the provision of reasonable accommodation when necessary to ensure the right to life, such as ensuring access of persons with disabilities to essential facilities and services...”[[71]](#footnote-71) This Committee has interpreted Article 6 of the ICCPR with reference to Article 10 of the CRPD, which provides that “States Parties reaffirm that every human being has the inherent right to life and shall take all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.” It is clear that the right to life includes obligations on states to ensure access to the social conditions necessary for meaningful enjoyment of the right.

With respect to assisted dying, this Committee’s General Comment on Article 6 states that it requires “robust legal and institutional safeguards to verify that medical professionals are complying with the free, informed, explicit and unambiguous decision of their patients, with a view to protecting patients from pressure and abuse.”[[72]](#footnote-72) Consistent with the General Comment, this Committee has previously recommended that states strengthen their safeguards regarding assisted dying.[[73]](#footnote-73)

The requirement for safeguards under Article 6 is highly relevant for persons with disabilities, given the civil, social and economic disadvantages they experience that contribute to their preventable suffering, and that may induce them to request MAiD at the end of life.

To meet the requirement under Article 6, safeguards must provide real options that actually ameliorate suffering and allow for meaningful alternatives to assisted dying. In her report to the Human Rights Council at its 43rd session, former Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas Aguilar, called for the Government of Canada to put into place adequate safeguards to ensure that persons with disabilities do not request assisted dying because of the absence of community-based alternatives and palliative care.[[74]](#footnote-74) A similar recommendation was made to Canada by the CRPD Committee in its 2017 Concluding Observations.[[75]](#footnote-75) The Committee expressed its concern about the adoption of MAiD based on disability and recommended that Canada ensure that people who seek MAiD at the end of life have access to alternative courses of action and the supports necessary to live a full life in the community.[[76]](#footnote-76)

Contrary to the CRPD Committee’s recommendation, Canada’s MAiD law requires that persons whose natural death is reasonably foreseeable only be provided with “information” about interventions and supports that might alleviate suffering. There is no explicit assurance that such services be available. There is no guaranteed right to access palliative care, in-home supports or other disability services and supports in Canada. The legislative language of these provisions carefully skirts any question of what happens when critical services and supports are not available, have excessively long waitlists or are only offered at levels that do not meet actual needs. With no assurance that conditions of civil, social and economic inequality will be directly and positively addressed, there is no procedural safeguard sufficient to bring the MAiD provisions for people whose death is reasonably foreseeable into compliance with Article 6. Canada’s MAiD regime falls short of the necessary institutional and legal safeguards to meet the requirements under Article 6. Without meaningful safeguards, persons with disabilities at the end of their lives are vulnerable to pressure to receive MAiD, contrary to Article 6.

We are, of course, concerned that under the expanded MAiD regime, persons with disabilities who are not near the end of their natural lives are also made vulnerable to MAiD by external pressure, coercion and inducement. However, for reasons outlined in the next section, we are of the view that no safeguards can save the amendments which provide for access to MAiD for persons who are not at the end of life. In their very intent and design, these amendments constitute a fundamental violation of the rights to life and equality protected under Articles 6 and 26.

## Recommended Questions for LOIPR

Despite serious concerns raised by disabled persons organizations and documented cases of persons with disabilities being induced to request MAiD when the conditions for a dignified and autonomy-respecting natural death are denied them, the Government of Canada maintains that MAiD does not violate the right to life of persons with disabilities.

* What new safeguards will the Government of Canada introduce to ensure that people with disabilities who request MAiD at the end of their lives have meaningful options for adequate, timely access to disability services and supports, community mental health supports, affordable accessible housing, income supports, specialized medical care, palliative care, home care and assistive devices necessary to live out their lives with dignity, thereby ensuring that the decision to request MAiD is truly voluntary, fully informed and that it is not the result of civil, social or economic deprivation?
* What resources and mandates is the Government of Canada providing to provincial and territorial governments to implement these new safeguards that fall within their jurisdictions?
* How, specifically, will the Government of Canada assess and report publicly on the effectiveness of these new safeguards?

# Contrary to Articles 6 and 26, MAiD for Persons with Disabilities Who are Not Dying Devalues their Lives and Contributes to Systemic Inequality

In their February 2021 Joint Communication to Canada, the UN Special Rapporteur on the Rights of Persons with Disabilities, the Independent Expert on the Enjoyment of all Human Rights by Older Persons, and the Special Rapporteur on Extreme Poverty and Human Rights stated that Canada’s current MAiD law risks, “... reinforcing (even unintentionally) ableist and ageist assumptions about the value or quality of life of persons with disabilities and older persons with or without disabilities.”[[77]](#footnote-77) Further they stated that, “(f)rom a disability rights perspective, there is a grave concern that, if assisted dying is made available for all persons with a health condition or impairment, regardless of whether they are close to death, a social assumption might follow (or be subtly reinforced) that it is better to be dead than to live with a disability.”[[78]](#footnote-78) They found that “(b)y expanding access to medical assistance in dying based on disability …. the policy would ... have a potentially discriminatory impact on persons with disabilities and older persons who are not at the end of their life or nearing death from natural causes ….”[[79]](#footnote-79)

An example is illustrative of the manner in which Canada’s current MAiD law specifically targets disability-related suffering for assisted death, thereby signalling in public policy that the lives of people with disabilities are less valuable than others. Imagine two people in Canada who both experience intolerable suffering due to homelessness, poverty, social isolation, and exposure to violence. Neither will die of natural causes in the near future, but one has a serious and incurable disability and the other does not. Under Canada’s current MAiD law, the disabled person could qualify for MAiD, while the nondisabled person would not. This is the case even though they experience the same intolerable suffering. Underlying the distinction between these two people is the discriminatory view that life with a disability may be a life worse than death. In this way the legislation reinforces negative stereotypes about living with a disability, thereby contributing to systemic ableism and negative social perceptions of persons with disabilities.

These societal implications are particularly concerning, in light of the existing ableism and inequality experienced by persons with disabilities in Canada, as detailed above. During Parliamentary hearings about Canada’s current MAiD legislation, persons with disabilities testified before lawmakers about the way in which the legislation reinforces ableist views about disability. Dr. Heidi Janz stated that:

“(p)eople with disabilities are at a higher risk of suicide due to systemic and internalized ableism, yet they face substantial barriers when trying to access suicide prevention services. Medical professionals overlook typical sources of stress. Problems arising from relationship breakdowns, depression and isolation are wrongly attributed to disability. The 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. In a truly just and progressive society, suicide prevention measures should be applied equally to all people."[[80]](#footnote-80)

Taylor Hyatt stated that:

"(b)reathing supports would be considered standard treatment for a non-disabled person in my situation, especially somebody in their mid-20s as I was. That's supposed to be the prime of your life. All the doctors seemed to see was a disabled woman alone, sick, tired, and probably tired of living. This is nothing new."[[81]](#footnote-81)

By expanding eligibility for assisted dying to people who are not near death, Canada’s MAiD legislation serves to reinforce rather than counteract these damaging social forces.

We emphasize that legislation that contributes to systemic societal ableism must never be considered consistent with Article 6 or 26 of the ICCPR. While Article 6 includes an obligation to ensure access to the essentials of life such as food, shelter, and water, it also includes measures to combat stigmatization associated with disabilities which can undermine access to health care.[[82]](#footnote-82) Article 26 requires states “... to take affirmative action in order to diminish or eliminate conditions which cause or help to perpetuate discrimination prohibited by the Covenant. For example, in a State where the general conditions of a certain part of the population prevent or impair their enjoyment of human rights, the State should take specific action to correct those conditions.”[[83]](#footnote-83) Article 26 should be interpreted with reference to Article 5 of the CRPD, which specifically addresses non-discrimination against persons with disabilities.[[84]](#footnote-84) The right to equality should account for the human rights model of disability -- “that disability is a social construct and impairments must not be taken as a legitimate ground for the denial or restriction of human rights”.[[85]](#footnote-85)

Central to the right to be free from discrimination is the need to combat negative stereotypes that undermine equality. In the context of disability, the right to be free from discrimination is closely related to Article 8 of the CRPD, which calls on States Parties to “promote positive perceptions and greater social awareness towards persons with disabilities” and to “combat stereotypes, prejudices and harmful practices” relating to persons with disabilities. In their February 2021 Joint Communication to Canada, the UN Special Rapporteur on the Rights of Persons with Disabilities, the Independent Expert on the Enjoyment of all Human Rights by Older Persons, and the Special Rapporteur on Extreme Poverty and Human Rights stated that, “... Article 8 envisages a positive policy eco-system that takes great care to ensure that otherwise sound and well-intentioned legislation does not indirectly pivot on, or subtly reinforce, ableist assumptions in society. It is hard to see how a legislative proposal that extends a right to medically assisted dying to persons with disabilities who are not themselves close to death could send a signal that is compatible with Article 8 (obligations to combat ableism) combined with Article 5 (obligation to secure equal respect for rights) of the CRPD.”[[86]](#footnote-86)

## Recommended Questions for LOIPR

* What new measures, funding and mandates will the Government of Canada commit to take to counteract the negative societal impacts of MAiD legislation, including devaluing the lives of persons with disabilities and contributing to systemic ableism?
* How will these measures specifically address those negative societal impacts?
* How will the Government of Canada monitor and report publicly on the effectiveness of these new measures in creating a culture of accessibility and inclusion sufficient to counteract the discriminatory impacts of the legislation on people with disabilities? What resources will the Government commit to such monitoring?

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# Lack of Adequate Data Collection and Monitoring to Understand Discriminatory Impact of MAiD on Persons with Disabilities

Historically, reliable and internationally-comparable data about the impact of living with a disability has been recognized as being sparse, incomplete, and inconsistent.[[87]](#footnote-87) In response, Article 31 of the CRPD requires States Parties to collect statistics and data to identify how CRPD rights are being implemented and to design programs and policies that give effect to the CRPD.[[88]](#footnote-88) The obligation to collect data under Article 31 is closely linked to all of the rights and duties inherent in the CRPD*.*[[89]](#footnote-89) Collected data must be used to identify and address the barriers faced by persons with disabilities in exercising their rights.

Article 31 requires collected data to reflect the social model of disability as articulated in the CRPD - a stark change from the medical model of disability.[[90]](#footnote-90) This means that the data collected must shift away from just measuring individual impairments to measuring the existence of socially constructed barriers (physical, communicative, attitudinal) that could prevent or impede a person’s full and effective participation in society on an equal basis with others.[[91]](#footnote-91) An intersectional approach must be taken in both the collection and dissemination of data to ensure that persons with disabilities who are subject to multiple forms of marginalization are identified.

All data collected should ensure the protection of confidential information. Article 31 requires states to publicly disseminate data in a format that is accessible to persons with disabilities.

To comply with Article 31, Canada must ensure that the data collected and disseminated about MAiD provide a true and accurate assessment of the impact that the legislation is having on persons with disabilities. The data collected must provide the means to demonstrate whether the safeguards in Canada’s MAiD legislation protect persons with disabilities from being pressured, induced or coerced into receiving MAiD. It must provide sufficient information to understand whether (and how) the practice of MAiD contributes to systemic inequality for persons with disabilities.

Adequate data collection and the dissemination of those data in a manner that enables the monitoring of MAiD is essential to determine whether Canada is complying with its obligations to protect the rights to life and equality under the ICCPR.

## Gaps in MAiD Data Collection and Dissemination

On November 1, 2018 federal regulations regarding MAiD data collection and monitoring came into force. These regulations created a pan-Canadian MAiD monitoring regime that set out the reporting requirements for physicians and nurse practitioners who provide MAiD, and pharmacists who dispense MAiD drugs.[[92]](#footnote-92) Because MAiD is delivered through provincial and territorial health care systems, the regulations outline a complex reporting process that differs from province to province and territory. The regulations require health care practitioners to collect and submit MAiD-related information to the federal Minister of Health.[[93]](#footnote-93) This data includes information about the patient, information about the medical practitioner and pharmacist, details about the request for MAiD and any referrals or transfers of the patient, documentation of procedural steps, information about the dispensing of a substance to effect MAiD and its self-administration or administration by a medical practitioner. The regulations also require the federal Minister of Health to publish a public report each year with some, but not all, of the data that are collected.[[94]](#footnote-94) Appendix 2 provides more detailed description of the data required to be collected and reported under these regulations.

Since the implementation of the MAiD data collection and monitoring regulations, it has become clear that there are gaps in data being collected about each MAiD death and gaps in the information being disseminated in the Minister of Health’s annual report. This results in an incomplete understanding of the impact that MAiD is having on persons with disabilities in Canada. Contrary to Article 31 of the CRPD, the regulations are wholly inadequate at identifying barriers created by and related to MAiD legislation that prevent persons with disabilities from exercising their rights to life and equality. The data collected under the federal regulations are not sufficient to provide assurance that Canada is complying with its obligations to protect the rights to life and equality under the ICCPR.

When the 2018 MAiD monitoring regulations were being developed, disabled persons organizations (DPOs) and disability groups called for a robust and holistic monitoring system.[[95]](#footnote-95) DPOs insisted that this system should include information that provided a fulsome understanding of the nature and extent of the suffering that motivates people to request MAiD. These data should also reflect the extent to which that suffering is the result of lack of services, supports and resources to ensure a dignified life in the community. DPOs called for information about the person’s income, social support network, whether or not the individual requesting MAiD had access to the services and supports they required, and the nature of their disability. Additionally, DPOs called for data regarding what alternative courses of action to relieve suffering had been identified and explored by the individual’s medical practitioner(s) and care team. This information would help to understand the supports that were available and whether the options presented provided actually ameliorated suffering and allowed for meaningful alternatives to assisted dying.

Much of the data that DPOs advocated for is not required to be collected by the regulations. Below, we outline just a few examples of gaps in MAiD data collection and dissemination. Many additional gaps exist.

**No information directly from the person requesting MAiD:** Current data collection provides an incomplete profile of persons with disabilities and their civil, social and economic circumstances, making it impossible to assess whether persons with disabilities are being pressured, coerced or induced to receive MAiD. For example, the regulations do not require the collection of a first-person narrative as to why MAiD is being requested. As recommended by DPOs, this information is necessary to understand the extent to which MAiD requests are motivated by preventable suffering linked to the absence of services, supports and resources.

**Incomplete demographic data:** Notably, disaggregated demographic data is collected in other policy areas, but demographic data about MAiD is incomplete. For example, income of persons receiving MAiD, immigration status/language spoken other than English or French, and information on social support networks are not currently collected. This information is necessary to ensure that low-income persons, racialized and immigrant persons, and socially isolated persons (with and without disabilities) are not over-represented in MAiD. Postal codes of residence are collected but need to be expanded to identify homeless persons (with and without disabilities) to ensure that this population is not over-represented in MAiD.

**Incomplete data about services and supports:** Data collected on whether a person receiving MAiD had access to palliative care and disability services and supports is incomplete. It does not include an assessment of what type of disability services and supports were received, what type of palliative care was received, from whom and the quality of that care. Data is not collected about access to specialized health practitioners such as geriatricians or specialists in care for persons with intellectual and/or developmental disabilities. This data would assist in understanding whether seniors (with and without disabilities) and persons with disabilities who have complex needs are over-represented in MAiD.

**Under-reporting of MAiD requests:** The MAiD Regulations require reporting about written requests for MAiD only. Various provincial and territorial MAiD coordination systems have been established to triage the intake of MAiD requests, which means that some requests do not meet the written request requirement and are thus not reported. Discussions about MAiD and assessments for MAiD that are not written are also not captured.[[96]](#footnote-96) This has resulted in incomplete data about who is requesting MAiD in Canada.[[97]](#footnote-97)

## Going forward, Data Collection and Dissemination Must Address Gaps Identified by Disabled Persons

When legislative amendments were passed to expand MAiD in March 2021, changes were also made to Canada’s data collection and reporting regime. These changes authorize the Minister of Health to develop additional regulations regarding the collection of information about unwritten MAiD eligibility assessments and information from pharmacists who may provide MAiD drugs to medical practitioners.[[98]](#footnote-98)  These amendments also allow for the development of federal regulations to collect data related to race, Indigenous identity and disability, and to seek to determine the presence of individual or systemic inequality.[[99]](#footnote-99)  The Government anticipates that data reflecting these changes will only be reported in 2024 or 2025,[[100]](#footnote-100) leaving several years during which MAiD will operate without government monitoring for inequality.

Despite these amendments, disability communities remain deeply concerned that existing and future data collection and monitoring requirements will fail to capture information necessary to understand the real impact of MAiD on persons with disabilities. To date data collection and measurement efforts have provided a superficial understanding of the impact that Canada’s MAiD regime has on persons with disabilities. “By the end of December 2019, over 13,000 Canadians died with medical assistance. For almost 10,000 of those MAiD cases, we have no publicly accessible evidence that the eligibility criteria and safeguards prescribed by law were respected.”[[101]](#footnote-101) Other stark examples of the inadequacy of data collection are the documented cases of persons with disabilities being pressured, coerced or induced to receive MAiD because of a lack of viable alternatives, described above. These cases did not come to light via the official MAiD data collection and monitoring regime. Instead, they were documented by media, family and friends, and community-based disability organizations.

Experience to date points to the need to collect not just data and statistics, but also human experiences of MAiD, in order to gain a fuller understanding of its impact on equity-seeking populations such as persons with disabilities. Human rights monitoring approaches would assist in gathering this type of information.

To comply with Article 31 of the CRPD, Canada must collect and publish data which provide a true and comprehensive assessment of the impact that MAiD legislation has on persons with disabilities. This is essential in order to determine whether Canada’s MAiD regime complies with its obligations to protect the rights to life and equality under the ICCPR.

In addition, Article 31 calls for the inclusion of persons with disabilities and their representative organizations in the collection, analysis and dissemination of data. Going forward, persons with disabilities must be meaningfully engaged in changes the Government of Canada makes to MAiD monitoring regulations and requirements. Changes to MAiD monitoring and dissemination regulations must address the identified data gaps and concerns of persons with disabilities.

## Recommended Questions for LOIPR

* What specific measures will the Government of Canada take to engage meaningfully and ongoingly with disabled persons regarding changes to MAiD data collection and monitoring regulations and requirements? Will the Government of Canada commit to ensuring that such changes address identified data gaps and concerns of persons with disabilities?
* How will the Government of Canada ensure that adequate data, including disaggregated demographic data, is collected and reported to truly and comprehensively understand the impact of MAiD on:
  + People with disabilities whose natural death is reasonably foreseeable and who request MAiD?
  + People with disabilities whose natural death *is not* reasonably foreseeable, and who request MAiD? and
  + People with disabilities who do not request MAiD but whose lives and self-perceptions are affected by a law and health care system that provide for terminating the lives of people like them, based on their disability?
* Will the Government of Canada commit to a human rights monitoring approach to the collection and dissemination of MAiD data?

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# Canada Has Not Fulfilled its Obligation to Address the Equality Concerns of Disabled Persons

Article 25 of the ICCPR protects the right to participate equally in consultations to make and amend laws. It recognizes the democratic right to be meaningfully engaged and involved in issues that affect one’s life. Articles 4(3) and 29 of the CRPD elaborate on this right, in the context of disability. Article 4(3) provides that, when developing legislation and policies that affect persons with disabilities, states must “...closely consult with and actively involve” them.[[102]](#footnote-102) The CRPD requires that states approach the process with an open mind, such that persons with disabilities are not “heard as a mere formality”.[[103]](#footnote-103) Democratic processes are undermined when governments enter into consultations with a predetermined outcome in mind.

When read with the right to equality (Article 26 of the ICCPR and Article 5 of the CRPD), it is clear that Articles 25 and 4(3) contemplate more than just government “consulting with” or listening to the concerns raised by persons with disabilities. Part of the obligation on states is to act to address those concerns, particularly when they are about violations of core human rights such as equality and the right to life. Gerard Quinn, Special Rapporteur on the Rights of Persons with Disabilities, expressed this in his testimony before Canada’s Senate. He urged the Senate Committee to “[l]isten closely to those most directly affected. Their antenna is highly attuned to ableism. When they see it, you should pause and reflect before proceeding.”[[104]](#footnote-104)

During Parliamentary hearings about the expansion of MAiD that renders all persons with disabling conditions potentially eligible for state-sanctioned death in ways that nondisabled persons are not, a significant number of persons with disabilities, disability organizations, and legal and medical experts made submissions regarding the discriminatory impact the legislation would have on individual persons with disabilities, and the manner in which the legislation would deepen existing ableism and negative stereotypes about the value of life as a disabled person.[[105]](#footnote-105) Minister David Lametti, Canada’s federal Justice Minister, defended the legislation by asserting that the additional safeguards of a “second track” of MAiD for people whose death is not reasonably foreseeable were an adequate response to these concerns.[[106]](#footnote-106) Canada continues to take this position.[[107]](#footnote-107)

In contrast, a number of disability organizations explicitly rejected this characterization, stating that that “...we did not at any time devise, nor did we endorse, the two-track approach of Bill C7.”[[108]](#footnote-108) They further explained that the legislation does not include “a meaningful commitment to ensuring that disabled Canadians nearing the end of our lives will never again have to endure the immense physical and existential suffering – the needless suffering – of such deplorable deprivation.”[[109]](#footnote-109) In public consultations held by the Government of Canada, persons with disabilities expressed similar sentiments, stating, for example, that “(h)aving a disability is not a fate worse than death, and disability is not a valid ‘cause of death’. The right to autonomy does not trump the right to live on an equal basis of others."[[110]](#footnote-110) Persons with disabilities have been clear that Canada has not complied with its obligation under Article 25 of the ICCPR and Article 4(3) of the CRPD to address the concerns of disability communities.

Article 4(3) also obligates states to make best efforts to receive the perspectives of diverse communities of persons with disabilities.[[111]](#footnote-111) This is critical since the lived experience of persons with disabilities “is both complex and diverse and there is no monolithic experience of having a disability.”[[112]](#footnote-112) Certain disabilities are less likely to be reflected in the literature and can be overlooked in research and policy development regarding persons with disabilities.[[113]](#footnote-113) Furthermore, persons with disabilities have distinct lived experiences that reflect multiple sites of discrimination.[[114]](#footnote-114)

The Government of Canada is currently engaged in a legislative review of MAiD and an expert study on the safeguards and protocols that will be required in two years when eligibility under the current law will extend to persons whose sole underlying disability is a mental illness. At the same time, the Government of Canada has, at the time of writing, initiated a formal parliamentary review to consider expanding MAiD further to include mature minors and persons who are no longer capable of consenting to MAiD but have made prior and capable advance requests. Each of these developments raises alarms about the normalization of death as a remedy for suffering, exclusively for persons with disabling conditions. As we confront the imminent possibility of waving the fundamental requirement for consent to MAiD, it is impossible to overstate the risks foreshadowed for people with cognitive and intellectual disabilities in Canada and the urgency with which civil society organizations and individuals committed to the protection of human rights and disability rights now seek to be heard.

Going forward, persons with disabilities must have ongoing opportunities to be meaningfully involved in reviews of MAiD legislation, changes to MAiD monitoring regulations, expert studies on expanding MAiD, and other such initiatives. Meaningful involvement requires ongoing opportunities to provide input that is seriously considered and appropriately addressed.

## Recommended Questions for LOIPR

* What specific measures will the Government of Canada take to ensure that persons with disabilities from diverse groups are meaningfully involved in reviews of MAiD legislation, changes to MAiD monitoring regulations, expert studies on expanding MAiD, and other such initiatives?
* How will the Government ensure that such measures provide more satisfactory levels of meaningful engagement than the consultative processes and structures that preceded the drafting and passage of the current MAiD law?
* Will the Government of Canada commit to addressing the concerns raised by persons with disabilities to ensure that MAiD does not violate the right to life and equality?

# APPENDIX 1: Summary of Canada’s MAiD Legislation

With the 2021 amendments, MAiD is now permitted for persons whose death is reasonably foreseeable and for persons who are not near the end of their natural life and who meet the eligibility criteria. To receive MAiD, a person:

* must be eligible for government-funded health services in Canada;[[115]](#footnote-115)
* be 18 or older and capable of making health-related decisions;[[116]](#footnote-116)
* have a “grievous and irremediable medical condition”[[117]](#footnote-117): this means that a person must have a serious and incurable illness, disease or disability[[118]](#footnote-118), be in an advanced state of irreversible decline in capability[[119]](#footnote-119), and have enduring physical or psychological suffering “that is intolerable to them and that cannot be relieved under conditions that they consider acceptable”;[[120]](#footnote-120)
* make a voluntary request for MAiD that is not the result of external pressure[[121]](#footnote-121); and
* after having been provided with information about ways to alleviate suffering, give informed consent to MAiD[[122]](#footnote-122).

In addition, for persons whose natural death is reasonably foreseeable, a medical practitioner must:

* ensure that the person’s request for MAiD was made in writing and signed and dated;[[123]](#footnote-123)
* ensure that the person was informed they have a grievous and irremediable medical condition;[[124]](#footnote-124)
* ensure that the request was signed and dated before an independent witness.[[125]](#footnote-125) This is a less stringent requirement than under the 2016 MAiD law, which required 2 witnesses;
* ensure the person was informed that they may at any time withdraw their request;[[126]](#footnote-126)
* ensure that a second independent medical practitioner provides a written opinion confirming that the person meets all the criteria;[[127]](#footnote-127)
* if the person has difficulty communicating, take all necessary measures to provide a reliable means by which the person can understand information provided to them and communicate their decision[[128]](#footnote-128); and
* immediately before providing MAiD, give the person an opportunity to withdraw their request.[[129]](#footnote-129)

For persons whose natural death is not reasonably foreseeable, a medical practitioner must fulfill the above requirements and the following additional requirements:

* if neither the medical practitioner nor the independent medical practitioner has expertise in the condition that is causing the person’s suffering, they must consult with another independent practitioner who does have that expertise;[[130]](#footnote-130)
* ensure that the person has been informed of the means available to relieve their suffering, including counselling services, mental health and disability support services, community services and palliative care and has been offered consultations with relevant professionals who provide those services;[[131]](#footnote-131)
* ensure that they have discussed with the person the reasonable and available means to relieve the person’s suffering and agree that the person has give serious consideration to those means;[[132]](#footnote-132) and
* ensure that there are at least 90 days between the day on which the person was assessed for eligibility for MAiD and the day on which MAiD is provided. This 90-day period can be shortened if the person will imminently lose their capacity to consent to MAiD.[[133]](#footnote-133)

# APPENDIX 2: Summary of Federal MAiD Data Collection and Monitoring Regulations

These regulations require health care practitioners to collect and submit MAiD-related information to the federal Minister of Health.[[134]](#footnote-134) In some provinces, this information is submitted directly to the federal Minister of Health; in other provinces, the data are submitted to a provincial or territorial authority and then provided to the federal government; and, in some provinces there is a hybrid approach.

Collected MAiD data includes:

* patients’: (1) date of birth, (2) sex, (3) health insurance number or province of residence and (4) postal code;[[135]](#footnote-135)
* information about the practitioner including (1) licence number, (2) whether they are a medical practitioner or nurse practitioner, (3) their specialty (if any), (4) the provinces/territories where they practice, and (5) whether the patient consulted them about health-related concerns before requesting MAiD;[[136]](#footnote-136)
* details about the request for MAiD including (1) the date, and (2) how the request was received (for example, from the patient themselves or through someone else, such as another practitioner or care coordination service);[[137]](#footnote-137)
* details about referrals or transfers of patient including the reason for the referral, e.g. whether the request was contrary to the practitioner’s conscience and beliefs and whether the practitioner believed that the patient was eligible for MAiD;[[138]](#footnote-138)
* patient’s eligibility for MAiD including (1) any consultations regarding eligibility, (2) which eligibility criteria were assessed and if the patient meets those criteria, (3) whether the patient received palliative care and if so for how long, (4) whether the patient received disability support services and if so for how long, (5) if the patient did not receive disability support services, whether those services were available, and (6) if the patient met the criteria at one time but did not at a later date and whether this was because of a loss of capacity to make healthcare decisions or because the practitioner became aware that the request was not voluntary;[[139]](#footnote-139)
* documentation of the procedural steps that are required in the context of a request for MAiD, including the date that the request was signed;[[140]](#footnote-140)
* information about the self-administration of a substance to effect MAiD including (1) the date that the substance was provided, (2) the place where the patient was staying, (3) whether the patient self-administered the substance, (4) the date and the place the substance was administered, (5) whether the practitioner was present at the time of administration, or (6) if the patient did not administer the substance whether the patient has died and the date of death;[[141]](#footnote-141)
* information about the administration of a substance by a practitioner to effect a request for MAiD including (1) the date and (2) the place where the substance was administered;[[142]](#footnote-142) and
* information about the dispensing of a substance to effect a request for MAiD including (1) the patient’s date of birth, (2) their health insurance number or usual place of residence, (3) information about the pharmacist’s licence and provinces/ territories where they practice, (4) the name and licence number of the practitioner who prescribed the substance or obtained it from the pharmacist, (5) the date the substance was dispensed, and (6) whether it was dispensed from a hospital or community pharmacy.[[143]](#footnote-143)

The regulations also require the federal Minister of Health to publish a public report each year with some, but not all, of the data that are collected.[[144]](#footnote-144) This public report must contain:

* the number of requests that were made and the results of those requests;
* the characteristics of patients, including medical characteristics;
* the nature of the intolerable physical or psychological suffering of patients who received MAiD;
* the reasons for which patients did not receive MAiD, including which of the eligibility criteria were not met by patients;
* the places in which medical assistance in dying was provided;
* time periods relating to the handling of requests for, and the provision of, MAiD;
* information as to whether practitioners consulted with other health care professionals or social workers regarding requests for MAiD;
* the nature of involvement of practitioners in requests and the provision of MAiD, including the respective involvement of medical practitioners and nurse practitioners;
* information as to whether patients consulted with practitioners concerning their health for a reason other than seeking MAiD before practitioners received their requests for MAiD;
* the methodology employed to arrive at any findings set out in the report;
* information on trends in written requests for, and the provision of, MAiD; and
* the period covered by the report.

1. *Criminal Code*, RSC 1986, c C-46, s 241.1, as amended by as amended by *An Act to amend the Criminal Code,* SC 2021, c 2 [*Criminal Code*] [↑](#footnote-ref-1)
2. *International Covenant on Civil and Political Rights*, 19 December 1966, 999 UNTS 171 (entered into force 23 March 1976, accession by Canada 19 May 1976) [*ICCPR*] [↑](#footnote-ref-2)
3. *Carter v Canada* (Attorney General), 2015 SCC 5 [*Carter*] [↑](#footnote-ref-3)
4. *Ibid* at paras 66, 86-88, 107, 121 [↑](#footnote-ref-4)
5. *Criminal Code*, RSC 1986, c C-46 s 241.2(1)(c), as amended by *An Act to amend the Criminal Code and to make related amendments to other Acts (medical assistance in dying)*, SC 2016, c 3 [↑](#footnote-ref-5)
6. Inclusion Canada, “Bill C-7 Through a Disability Lens” (2020), online (pdf): <https://inclusioncanada.ca/wp-content/uploads/2020/11/Bill-C-7-Through-a-Disability-Lens.pdf> [↑](#footnote-ref-6)
7. *Truchon v Procureur général du Canada*, [2020] QJ No 1553 [↑](#footnote-ref-7)
8. *Criminal Code*, above, s 241.2(b) [↑](#footnote-ref-8)
9. *Criminal Code*, above, s 241.2(1)(d) [↑](#footnote-ref-9)
10. *Criminal Code*, above, s 241.2(1)(d), 241.2(1)(e), 242.2(3), 242.2(3.1) [↑](#footnote-ref-10)
11. *Criminal Code*, above, s 242.2(3.1). The waiting period can be shortened if the person will imminently lose their capacity to consent to MAiD: s 242.2(3.1)(i) [↑](#footnote-ref-11)
12. *Criminal Code*, above, s 241.2(2.1); C-7, *An Act to amend the Criminal Code* (medical assistance in dying), 2nd Sess, 43rd Parl, 2021, preamble (assented to 17 March 2021); Government of Canada, “Canada’s New Medical Assistance in Dying (MAiD) Law” (19 March 2021), online: <https://www.justice.gc.ca/eng/cj-jp/ad-am/bk-di.html> [↑](#footnote-ref-12)
13. UNCRPD, “Concluding observations on the initial report of Canada” (8 May 2017) UN Doc CRPD/C/CAN/CO/1 at para 23 [UNCRPD 2017 Concluding Observations]; UNCRPD, “List of issues prior to the submission of the combined second and third periodic reports of Canada” (5 November 2019) UN Doc CRPD/C/CAN/QPR/2-3 at para 9 [↑](#footnote-ref-13)
14. UNHRC, “Visit to Canada: Report of the Special Rapporteur on the Rights of Persons with Disabilities” (19 December 2019) UN Doc A/HRC/43/41/Add.2 UN [Special Rapporteur Visit to Canada] [↑](#footnote-ref-14)
15. “Mandates of the Special Rapporteur on the rights of persons with disabilities; the Independent Expert on the enjoyment of human rights by older persons; and the Special Rapporteur on extreme poverty and human rights” (3 February 2021) UN Doc OL CAN 2/2021 [February 2021 Joint Communication to Canada] [↑](#footnote-ref-15)
16. *Convention on the Rights of Persons with Disabilities,* 13 December 2006, 2515 UNTS 3 (entered into force 3 May 2008, Convention ratified by Canada on 11 March 2010, Optional Protocol ratified by Canada on 3 December 2018) [*CRPD*] [↑](#footnote-ref-16)
17. Emily Kakoullis & Yoshikazu Ikehara, “Article 1: Purpose” in Bantekas, Ilias, Michael Ashley Stein, and Dimitris Anastasiou, eds, *The Convention on the Rights of Persons with Disabilities: A Commentary* (Oxford: Oxford University Press, 2018) at 36 [↑](#footnote-ref-17)
18. UNHRC, “Visit to Canada: Report of the Special Rapporteur on the Rights of Persons with Disabilities” (19 December 2019) UN Doc A/HRC/43/41/Add.2 UN at para 69 [↑](#footnote-ref-18)
19. *Ibid.* [↑](#footnote-ref-19)
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111. UNCRPD General Comment No 7, above at para 50. This includes organizations representing children and women with disabilities, in addition to those representing a wide diversity of actual or perceived disabilities (para 28). To this end, the UN Committee on the Rights of Persons with Disabilities has established criteria for representative organizations that participate in law-making processes, relating to their: goals to pursue the rights of persons with disabilities; employees and representatives being persons with disabilities; lack of affiliation with political parties and public authorities, and reflection of a diversity of backgrounds, whether they are focused on an actual or perceived disability or all persons with disabilities (para 11). [↑](#footnote-ref-111)
112. DAWN “More Than a Footnote”, above at 23 [↑](#footnote-ref-112)
113. *Ibid* at 17 [↑](#footnote-ref-113)
114. Carol Aylward, “Intersectionality: Crossing the Theoretical and the Praxis Divide” (2010) 1:1 Journal of Critical Race Inquiry 1 at 16-17. For example, in Canada “[n]early 2.1 million women (14.9%) […] aged 15 or older reported having one or more disabilities that limited them in their daily activities in 2012”: Amanda Burlock, “Women with Disabilities” (2017) Statistics Canada, online: [https://www150.statcan.gc.ca/n1/pub/89-503-x/2015001/Article/14695-eng.htm](https://www150.statcan.gc.ca/n1/pub/89-503-x/2015001/article/14695-eng.htm) The Native Women’s Association of Canada also stated in 2018 that, “[u]pwards of 450,000 Indigenous people identify as having a disability, functional, or activity limitation, but it is unknown how many of those people are women, girls, or gender diverse because of inaccurate and insufficient data”: Native Women’s Association of Canada, “Accessibility and Disability for Indigenous Women, Girls, and Gender Diverse People” (2018) at 5, online: <https://www.nwac.ca/wp-content/uploads/2018/05/Accessibility-Final-Report_1.pdf> In addition, 3.7% of Canadian children under the age of fifteen reported a disability in 2006: Statistics Canada, “Participation and Activity Limitation Survey 2006: Families of Children with Disabilities in Canada” (2006), online: <https://www150.statcan.gc.ca/n1/pub/89-628-x/89-628-x2008009-eng.htm> [↑](#footnote-ref-114)
115. *Criminal Code*, above, s 241.2(1)(a)) [↑](#footnote-ref-115)
116. *Ibid*, s 241.29(1)(b) [↑](#footnote-ref-116)
117. *Ibid*, s 241.2(1)(c) [↑](#footnote-ref-117)
118. *Ibid*, s 241.2(2)(a) [↑](#footnote-ref-118)
119. *Ibid*, s 241.2(2)(b) [↑](#footnote-ref-119)
120. *Ibid*, s 241.2(2)(c) [↑](#footnote-ref-120)
121. *Ibid*, s 241.2(1)(d) [↑](#footnote-ref-121)
122. *Ibid*, s 241.2(1)(e) [↑](#footnote-ref-122)
123. *Ibid*, s 241.2(3)(b)(i) [↑](#footnote-ref-123)
124. *Ibid*, s 241.2(3)(b)(ii) [↑](#footnote-ref-124)
125. *Ibid*, s 241.2(3)(c) [↑](#footnote-ref-125)
126. *Ibid*, s 241.2(3)(d) [↑](#footnote-ref-126)
127. *Ibid*, s 241.2(3)(e), (f) [↑](#footnote-ref-127)
128. *Ibid*, s 241.2(3)(g) [↑](#footnote-ref-128)
129. *Ibid*, s 241.2(3)(h) [↑](#footnote-ref-129)
130. *Ibid*, s 241.2(3.1)(e.1) [↑](#footnote-ref-130)
131. *Ibid*, s 241.2(3.1)(g) [↑](#footnote-ref-131)
132. *Ibid*, s 241.2(3.1)(h) [↑](#footnote-ref-132)
133. *Ibid*, s 241.2(3.1)(i) [↑](#footnote-ref-133)
134. *MAiD Monitoring Regulations*, above, s 16 [↑](#footnote-ref-134)
135. *Ibid,* schedule 1 [↑](#footnote-ref-135)
136. *Ibid* [↑](#footnote-ref-136)
137. *Ibid* [↑](#footnote-ref-137)
138. *Ibid*, schedule 2 [↑](#footnote-ref-138)
139. *Ibid*, schedule 3 [↑](#footnote-ref-139)
140. *Ibid*, schedule 4 [↑](#footnote-ref-140)
141. *Ibid*, schedule 5 [↑](#footnote-ref-141)
142. *Ibid*, schedule 6 [↑](#footnote-ref-142)
143. *Ibid*, schedule 7 [↑](#footnote-ref-143)
144. *Ibid,* s 13 [↑](#footnote-ref-144)