

Bill C:7 Through a Disability Lens

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By:

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People with Disabilities in Canada – Situating the Debate

22% of Canadians identify as having one or more disabilities. People with disabilities are diverse; all bodies are fragile and disability does not discriminate. At the same time, however, some marginalized groups experience higher than average rates of disability. For instance, 32% of First Nations people living off reserve have a disability¹.

Those who do have a disability must navigate deep-rooted systemic inequality and discrimination. Canada has a long history of institutionalization, segregation, eugenics, and of considering people with disabilities to be less-than-human. Today, ableism manifests as people with disabilities being twice as likely to have experienced hidden homelessness,² to be living in poverty³, and to have experienced violence⁴, and as people with even mild disabilities being six times as likely to be unemployed⁵.

This often results in basic needs going unmet. The 2017 Canadian Survey on Disability revealed that 1.6 million people (1 in 4) were unable to afford necessary aids, devices, or prescriptions.⁶ Some live with physical pain.

Canada is falling short of its commitments under the UN CRPD to uphold the rights and inherent dignity of all people with disabilities across jurisdictions and from coast to coast⁷.

And yet, against this backdrop of adversity and exclusion, people with disabilities contribute to our communities and cultures, most often living good and meaningful lives. People with disabilities are generally happy and find their lives to be worth living⁸.

In wrestling with whether or not Medical Assistance in Dying (MAiD) should be provided to a person with a disability on the basis of their suffering, we must make space for all of these truths: that we may all someday acquire a disability, that people with disabilities often experience hardship, inequality and discrimination based on their disability or intersecting

¹ Tara Hahmann, Ph.D., Nadine Badets, and Jeffrey Hughes. 2019. Indigenous people with disabilities in Canada: First Nations people living off reserve, Métis and Inuit aged 15 years and older. Aboriginal Peoples Survey. Statistics Canada. <https://www150.statcan.gc.ca/n1/pub/89-653-x/89-653-x2019005-eng.htm>

² Rodrigue, Samantha. 2016. Insights on Canadian Society Hidden homelessness in Canada. Statistics Canada. <https://www150.statcan.gc.ca/n1/pub/75-006-x/2016001/article/14678-eng.htm>

³ Morris, Stuart, Gail Fawcett, Laurent Brisebois, Jeffrey Hughes. 2018. A demographic, employment and income profile of Canadians with disabilities aged 15 years and over, 2017. Canadian Survey on Disability. Statistics Canada. <https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2018002-eng.htm>

⁴ Cotter, Adam. 2018. Violent victimization of women with disabilities. Gene, 2014 ral Social Survey on Victimization. Statistics Canada. <https://www150.statcan.gc.ca/n1/pub/85-002-x/2018001/article/54910-eng.htm>

⁵ Raso, Katie. 2018. Disability and the Job Churn. Canadian Centre for Policy Alternatives. <https://bit.ly/3jlnw78>

⁶ Morris, Stuart, Gail Fawcett, Laurent Brisebois, Jeffrey Hughes. 2018. A demographic, employment and income profile of Canadians with disabilities aged 15 years and over, 2017. Canadian Survey on Disability Reports. Statistics Canada. <https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2018002-eng.htm>

⁷ See article 4(5)

⁸ McConnell, David, Lyndsey Hahn, Amber Savage, Camille Dube, Elly Park. 2016. Suicidal Ideation Among Adults with Disability in Western Canada: A Brief Report. Community Ment Health J 52:519–526

marginalized identities, and, fundamentally, that people with disabilities can and do live good lives.

Community Landscape

People with disabilities have been at the centre of Canada's MAiD debates. Some have been vocal in pushing for legislative reform in order to obtain the "right" to die by MAiD when suffering becomes intolerable⁹. Others have been sounding the alarm, untrusting of political, legal, and medical systems that would uncritically tilt toward MAiD as the expected response to a disabling condition, because of deeply embedded presumptions that disability diminishes the quality and value of life. Canada's national disabled persons' organizations remain united in resisting the expansion of MAiD on the basis of disability or suffering outside of end-of-life contexts.

Recognizing that opinions diverge, biases exist, and the stakes are high, it is particularly important to thoroughly and systematically review the legislation before Parliament.

Applying a Disability and Inclusion lens to Bill C-7

The following is a preliminary analysis of Bill C-7 as seen through a disability and inclusion lens. Such a lens brings into view the sources of disadvantage that result in unequal opportunities and outcomes for people with disabilities, allowing for the tools of public policy to overcome these disadvantages.

To be clear, the below analysis focuses on the question of whether to modify MAiD regulations to provide for people with disabilities who are suffering but not near death from natural causes to die by MAiD. It takes as a given that those who are at the end of their natural lives have access to MAiD and in particular that people with disabilities have equal access to MAiD when at the end of life.

In particular, we draw the following questions from the Policy and Program design section of the Institute for Research and Development on Inclusion and Society (IRIS) Disability and Inclusion lens¹⁰.

1. In what ways does the policy framework, directly or indirectly, affect people with disabilities and their families?

Bill C-7 introduces a **two track approach** to assisted dying in Canada.

⁹ We put "right" in quotation marks, noting that the right to die when suffering becomes intolerable has not been afforded to all Canadians. While suicide remains decriminalized in that it is not to be punished, suicide prevention initiatives aim to prevent death based on suffering.

¹⁰ Bach, Michael, and Don Gallant. 2012. Disability and Inclusion Based Policy Analysis. Institute for Research and Development on Inclusion and Society. <https://irisinstitute.ca/wp-content/uploads/sites/2/2016/07/Disability-and-Inclusion-Based-Policy-Analysis.pdf>

Track one presents a less-stringently-safeguarded version of Canada's existing **MAiD** regime. The conditions of access outlined in track one would be available only to those whose natural death is reasonably foreseeable.

New to Bill C-7, applicants in both track one and track two would be able to have their applications witnessed by one independent witness (rather than two as is the eligibility criterion in the current legislation); and this one witness could be a paid personal or health care worker. Bill C-7 further proposes that those in track one be offered MAiD by advance consent and that applicants not be required to spend any minimum time reflecting on their decision to pursue MAiD.

These changes to the track one eligibility may put people with disabilities at risk. Power dynamics between paid staff and a person with a disability are rarely neutral. By simultaneously reducing the number of required witnesses and accepting paid staff as independent witnesses, Bill C-7 is making people with disabilities - particularly those without adequate support networks of friends and family - vulnerable to MAiD. Further, MAiD by advanced consent is at its core decision making by proxy; this is threatening to people with intellectual and developmental disabilities because it in effect establishes a legal framework for MAiD via a substitute decision maker.

Track two introduces, for the first time, what could be called **Physician Assisted Suicide (PAS)** in Canada. Some argue for this change in semantics because under track two, a person's death would not need to be reasonably foreseeable. **Indeed, under track two, Bill C-7 is not facilitating a hastened end to an inevitable and imminent death; instead it is facilitating an end to an otherwise open-ended span of life¹¹.**

Many people with grievous and irremediable medical conditions, including many people with disabilities, will be eligible for MAiD under track two. Beyond providing MAiD outside of end of life circumstances (risks will be outlined in-depth below), Bill C-7 also proposes to reduce the number of independent witnesses, accepting here as well paid personal or health care workers as witnesses.

In an attempt to offset these more lax eligibility requirements, Bill C-7 introduces three new safeguards. One of two assessing practitioners would need to be an expert in the condition that causes the person's suffering. A 90 day assessment period would need to be completed (except in cases where loss of capacity is anticipated). And a person would need to be informed of and have adequately considered supports that could ease their suffering.

¹¹ Friesen, Pheobe. 2020. Medically Assisted Dying and Suicide: How Are They Different, and How Are They Similar? The Hastings Centre Report. <https://doi.org/10.1002/hast.1083>

These safeguards do not go far enough to compensate for the requirements that have been removed - namely an end of life requirement.

By requiring that at least one assessor be an expert in the condition that causes a person's suffering, Bill C-7 implies that a person's disability is de facto the cause of their suffering. Although a careful reading of the current law requires that a person's suffering must stem from their medical condition, there is no express acknowledgement of this requirement in the current law and regulations, nor in policy and practice guidelines that regulate the provision of MAiD. Given this fact, it is worrisome that MAiD may be authorized by practitioners who fail to discern between suffering that arises from a medical condition and suffering that arises from social deprivation. A person with a disability may be suffering due to isolation, poverty, institutionalization, feeling like a burden to others, or any other reason, related or unrelated to their disability. It is both discriminatory and dangerous to presume that a person's suffering stems from their disability without a careful and unbiased inquiry into the nature of that person's suffering.

Sudden onset of disability is known to come with a difficult and, for some, lengthy period of adjustment. This adjustment period is known to last up to two years before a person begins to adapt and adjust not only to altered circumstances and capacities, but to new ways of living, of seeing oneself, contributing and finding meaning and belonging. 90 days is hardly long enough to ensure that a person is given the opportunity to adjust to their disability; 90 days is also not long enough to make it off of waitlists for a number of crucial community-based disability and social supports.

For people with disabilities, their families, and allies, the requirement to "be informed" of counselling, mental health supports, disability supports, community services, and palliative care and to have "adequately considered" their impact is perhaps the most insulting suggestion of the bill. It is insufficient, if not cruel, to tell a suffering person about all the services that may improve their quality of life and end their suffering without ensuring that those services be accessible, affordable, and available in a timely manner.

To this point, MAiD has been restricted to **end of life** circumstances. All those who have died have shared the common experience of approaching death. In this way, the end of life requirement has preserved fundamental principles of equality by recognizing disability as a characteristic that is relevant but not determinative of MAiD eligibility.

Under Bill C-7, for those who are not nearing death, having a disability would itself serve as the justification for the termination of life in a way that **no other Charter protected personal characteristic** could.

If Bill C-7 is approved as written, when people who *do not* have an illness, disease, or disability are unable to secure dignity in their lives and suffer to the point of wanting to die, they will be met with crisis supports and suicide prevention.

By contrast, when people who *do* have an illness, disease, or disability are unable to secure dignity in their lives because of structural barriers and suffer to the point of wanting to die, Canada will respond in a second very different way - by endorsing death through MAiD.

People with disabilities have historically been undervalued in Canada. Stereotypes, stigmas, and discriminatory views about life with a disability continue to shape the way life with a disability is envisioned even today. People with disabilities cannot afford to be unintentionally excluded from the normative practice of suicide prevention. Beyond the inevitable loss of human life, there is a significant risk of furthering the social devaluation of life with a disability.

See constitutional lawyer [Nicolas Rouleau](#) present on equitable responses to suffering.

2. What are the underlying values and assumptions of the policy and are they consistent with full inclusion and participation?

MAiD remains an exemption from the criminalization of assisted suicide in Canada. While suicide is not illegal in Canada, it is certainly actively prevented. Therefore, if Bill C-7 is passed Canada will need to be confident in distinguishing between suicidality and a "rational" request for MAiD.

This is tricky for people with disabilities for at least three reasons:

1. **People who do not have disabilities tend to rate the quality-of-life of people with disabilities as lower than do people with disabilities themselves.** Medical professionals might be more likely to assume that a person with a disability's desire to die is rational.
2. **People with disabilities face barriers in accessing mental health services.** They may be less likely to have a known history of mental illness. This is in part because of the assumption that suffering is an inherent part of life with a disability.
3. **For many people with disabilities, suffering is in fact real and rational, but decidedly not irremediable.** People suffer from gaps in community-based health and disability supports, long-term care homes that limit choice, privacy, independence, and relationships, isolation, exclusion, poverty, violence and abuse, feeling like a burden to others, and/or unmanaged pain.

Bill C-7 appears to be premised on flawed assumptions. Notable among these are the following:

- That suicides are never rational. However, and tragically, suicides are often very rational and well-considered expressions of despair.
- That when there is no medical cure or treatment to alleviate the suffering of people with disabilities, their suffering is by definition irremediable. This assumption too, is categorically false. Policy determinations of allocation and eligibility for social supports and intervention are almost always within the capacity of the state to deliver, once jurisdictional and bureaucratic impediments are overcome.

Bill C-7 changes the way that we respond to the suffering of people with disabilities who are not dying.

Many Canadians suffer rationally. Some suffer to the point of wanting to die, perhaps because they face homelessness, bankruptcy, or unemployment, or because they want to escape abuse, grief, or loneliness. **Canada rightfully does not intend to provide MAiD to everyone who suffers.**

Bill C-7 would create a dynamic in Canadian society where we respond to the suffering of a person with a disability differently than the suffering of a person without a disability. What stereotypes and assumptions underpin this distinction?

Maybe Canada is of the view that the suffering of people with disabilities is innate, and not also circumstantial?

Some of the most outspoken advocates for expanding access to MAiD in Canada are seeking to avoid living a dehumanizing and isolated life in an institution. Others are seeking to avoid a life of poverty. In these instances, without a tangible vision for an affordable and accessible alternative, death is being pursued as a concrete and readily attainable source of dignity. Sadly, it is not completely surprising that people, or in this case legislation, would implicitly assume that disability is itself a source of suffering. Such assumptions are deep-rooted.

Maybe Canada is of the view that it is natural or reasonable for a person with a disability to want to die?

When a person who does not have a disability wants to die, we don't first assess whether or not their desire to die is well thought out. For example, we, thankfully, don't turn to indigenous communities who have been impacted by generations of colonial violence, or to LGBTQ2S+ people who have felt familial and community rejection and question whether or not their hardship is a reasonable enough reason to die. We strive to intervene with compassion.

Categorically providing MAiD to people with disabilities who are suffering, while not providing MAiD to people without disabilities who are suffering may only be underpinned by ableism (a deeply embedded ethos of discrimination based on disability).

Up to this point, where MAiD has been made available only in end of life circumstances, making **palliative care** available to Canadians has been a key priority of elected officials. Though Canadians have a greater right to MAiD (access is legally protected) than they do to palliative care (access is not legally protected), Canadian political discourse continues to champion palliative care as the key alternative to MAiD.

For people with disabilities, if MAiD were to be made available outside of end of life circumstances, palliative care (though important) would not necessarily be the most needed alternative care option. Though Bill C-7 does include the safeguards of being “informed of” and “appropriately considering” necessary disability (and other) supports - a nod toward the needs of Canadians with disabilities - the legislation does not guarantee their provision.

A fundamental assumption of Bill C-7 is that people with disabilities have equitable access to services and supports that reduce suffering, and that when services and supports that may reduce suffering are identified, they will be available and affordable. Sadly, by and large this is not true. Barriers to access including cost, waitlists, societal devaluation, and ableism stand in the way.

Indeed, reflecting on her 2019 visit to Canada, the UN Special Rapporteur on the rights of persons with disabilities commented that they are “extremely concerned about the implementation of the legislation on medical assistance in dying from a disability perspective. She learned that there is no protocol in place to demonstrate that persons with disabilities deemed eligible for assistive dying have been provided with viable alternatives.”¹²

3. Are policy goals framed in inclusive ways?

- **Are some or all people with disabilities excluded – by design or unintentionally?**
- **If there are exclusions, is there a justifiable rationale consistent with equality rights, nondiscrimination and ameliorative programming (for example, programs targeted to people with ‘severe’ disabilities only)?**

To this point, people who are suffering but not nearing death from natural causes have been prevented from accessing MAiD. This includes people with disabilities who are suffering but not nearing death from natural causes.

¹² UN. Report of the Special Rapporteur on the rights of persons with disabilities on her visit to Canada. 2020. <https://undocs.org/pdf?symbol=en/A/HRC/43/41/ADD.2>

This exclusion is intentional and is justified by equality rights and principles of nondiscrimination. **Canada's current MAiD legislation maintains that "it is important to affirm the inherent and equal value of every person's life and to avoid encouraging negative perceptions of the quality of life of persons who are elderly, ill or disabled." Restricting MAiD to end of life is the only way to achieve this goal.** The Supreme Court of Canada has not been given the opportunity to test the constitutionality of an end of life requirement serving to preserve the equality of people with disabilities.

People who are not nearing death from natural causes have intentionally been excluded from accessing MAiD in keeping with Canada's suicide-prevention goals. As a nation, we do not endorse death as a solution to suffering. Accordingly, in the spirit of equality and nondiscrimination, it is imperative that we do not introduce death as a solution to suffering for people with disabilities.

Doing so would convey that life with a disability is a life worse than death, which will feed into existing negative views of life with disability. Further, the stigma associated with disability being portrayed as a life worse than death will undoubtedly be internalized by people with disabilities themselves.

Bill C-7, on the other hand, excludes specifically people whose sole underlying medical condition is a mental illness. This exclusion is welcome and necessary. The disability community is pleased to see the legislation recognize the complexity of mental illness. We would hope that Canada would extend that understanding to all Canadians with life left to live who are suffering to the point of wanting to die.

4. Are policy goals based on evidence and reflective of good practices that address the needs of and barriers faced by people with disabilities?

Bill C-7 makes reference to Canada's commitment to the UN CRPD.

In a report on the impact of ableism in medical and scientific practice, UN Special Rapporteur on the Rights of Persons with Disabilities, Catalina Devandas-Aguilar clearly stated that "If assisted dying is to be permitted, it must be accompanied by strong measures to protect the right to life of persons with disabilities. First, access to assisted dying should be restricted to those who are at the end of life; having an impairment should never be a reason for assisted dying to be permitted. Second, the free and informed consent of persons with disabilities must be secured on all matters relating to assisted dying and all forms of pressure and undue influence prevented. Third, access to appropriate palliative care, rights-based support, home care and other social measures must be guaranteed; decisions about assisted death should not be made because life has been made unbearable through lack of choices and control. Fourth, accurate information about the prognosis and availability of peer-support counselling

must be provided. Fifth, accountability regulations must be established requiring collection and reporting of detailed information about each request and intervention for assistance in dying¹³.

Bill C-7 does not meet these minimum standards as articulated by the UN.

In order for future legislative decisions on MAiD to be truly based in evidence, Canada must now include better monitoring provisions in Bill C-7.

“In order to understand whether, in authorizing the terminations of human lives through MAiD, the legislative regime has the effect of discriminating against persons with disabilities or vulnerable individuals we recommend that the legislation require that the Minister make regulations as follows. The legislation must require that in all MAiD cases:

- MAiD Practitioners must report in appropriate detail any and all factors in a patient’s living conditions or life circumstances that may be causing or compounding their suffering.
- MAiD Practitioners must specifically report other treatments or interventions, including but not limited to palliative care, disability supports, income assistance, counselling, assistive technology, communication supports and environmental accommodations that were offered to relieve their patient’s suffering, and the steps taken to make them available.
- The monitoring and reporting system must not rely solely on what MAiD Practitioners have to say about their patients and the practice of MAiD. Patients must be supported to offer their own perspectives if they wish. Similarly, members of a patient’s primary health care team must be permitted to contribute their knowledge and insights as well.
- The monitoring and reporting system must provide us with a deeper understanding of the reasons that patients choose MAiD.
- The monitoring and reporting system must provide sufficient information to the public so that our government can be held accountable for achieving the law’s objectives to respect autonomy and protect people from harm.”

¹³ UN. Special Rapporteur on the Rights of Persons with Disabilities. 2020. Report on the impact of ableism in medical and scientific practice.

<https://www.ohchr.org/EN/Issues/Disability/SRDisabilities/Pages/BioethicsDisabilities.aspx>

5. Have people with disabilities and their families, and their organizations, effectively participated in identifying their needs, barriers experienced, and desired policy goals?

- **Are people with disabilities, their families and organizations actively and meaningfully engaged in policy development?**

- **Are public consultations about the policy held in accessible venues? Are they conducted in plain language?**

While a few people with disabilities were invited to participate in early roundtable consultations on Bill C-7, several have reported their experience as feeling tokenistic and perfunctory. Similarly, although people with disabilities undoubtedly participated in the online survey of MAiD, these consultations were not necessarily inclusive safe spaces for sharing of vulnerability and people with disabilities' "voices from the margins" were largely not disaggregated from the opinions of the whole.

With the exception of one in-person disability-specific consultation on MAiD held in BC, the remainder of in-person roundtables were not safe spaces to discuss MAiD in it's full complexity. People with disabilities and their allies were often a minority voice in a room of passionate pro-MAiD advocates.

The online survey consultation on MAiD did not gather data on a person's disability status. The only demographic data captured was whether a respondent lived in a rural or urban area. It is impossible therefore for Canada to have an adequate understanding of the perspectives of people with disabilities¹⁴.

Informed by the systemic exclusion that people with intellectual and other disabilities and marginalized groups face, the Institute for Research and Development on Inclusion and Society works to seed and support transformative social development.

Guided by principles of full inclusion and human rights, we conduct research to identify issues and policy options, foster social innovation to re-imagine inclusion, and strengthen capacity and leadership for transformative change.

¹⁴ Voices from the Margins. 2020. Vulnerable Persons Standard. <https://static1.squarespace.com/static/56bb84cb01dbae77f988b71a/t/5f9065e56d65272858143fca/1603298789807/Voices+from+the+Margins.pdf>

14. Frazee, Catherine. 2020. Medical Assistance in Dying, Public Confidence, and the Lesson of the Driverless Car. <http://www.vps-npv.ca/blog>