

# Plagued to Death by Ableism: What the COVID-19 Pandemic and the Expansion of Eligibility for MAID Reveal About the Lethal Dangers of Medical and Systemic Ableism in Canada

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TÉMOIGNAGE / PERSPECTIVE

# Plagued to Death by Ableism: What the COVID-19 Pandemic and the Expansion of Eligibility for MAID Reveal About the Lethal Dangers of Medical and Systemic Ableism in Canada

Heidi Janz<sup>a</sup>

## Résumé

Dans cet article, je m'appuie sur mes recherches et mon expérience en tant qu'éducateur et défenseur de l'éthique du handicap pour démontrer que la réponse du Canada au COVID-19 et l'élargissement de l'éligibilité à l'AMM sont des symptômes du capacitisme médicale et systémique qui afflige la société canadienne. Je conclus par une réflexion sur le danger permanent que représente pour les personnes handicapées le capacitisme eugénique déguisé en autonomie dans un Canada où le COVID-19 est peut-être en train de disparaître, mais où la contagion du capacitisme devenu mortel grâce à l'AMM continue de se répandre.

## Mots-clés

capacitisme, discrimination systémique, COVID-19, aide médicale à mourir, AMM

## Abstract

In this paper, I draw on my research and experience as a disability ethics educator and advocate in order to demonstrate that both Canada's COVID-19 response and its expansion of eligibility for MAID are symptoms of the medical and systemic ableism that afflicts Canadian society. I conclude with a consideration of the enduring danger that eugenic ableism disguised as autonomy poses for people with disabilities in a Canada where COVID-19 may be waning, but where the contagion of ableism turned lethal through MAID continues to spread.

## Keywords

ableism, systemic discrimination, COVID-19, medical assistance in dying, MAID

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## INTRODUCTION

The year 2020, and the advent of COVID-19, ushered in a time of new peril for disabled people in Canada. Government and public health officials repeated their daily mantra "We're all in this together" while at the same time creating policies and legislation which made it clear that disabled Canadians were not part of the "we." Provinces quietly developed Critical Care Triage Protocols that prohibited many disabled people from receiving critical care in the event that a surge in severe COVID-19 cases outstripped available resources, and at the national level, government pushed through an expansion of Medical Assistance in Dying (MAID) despite overwhelming opposition from major disability rights organizations, scholars, activists and the United Nations.

In this paper, I draw on my research and experience as a disability ethics educator and advocate in order to demonstrate that both Canada's COVID-19 response and its expansion of eligibility for MAID are symptoms of the medical and systemic ableism that afflicts Canadian society. I conclude the paper with a consideration of the enduring danger that eugenic ableism disguised as autonomy poses for people with disabilities in a Canada where COVID-19 may be waning, but where the contagion of ableism turned lethal through MAID continues to spread.

## WHAT IS ABLEISM?

Ableism can be defined as prejudice and discrimination against people with disabilities based on the belief that typical abilities are superior. At its heart, ableism is rooted in the assumption that disabled people require 'fixing' and defines people by their disability. Like racism and sexism, ableism classifies entire groups of people as 'less than,' and perpetuates harmful stereotypes, misconceptions, and generalizations about people with disabilities (1). Clear yet unacknowledged, evidence of ableism can be seen in everything from the way in which buildings are built to exclude people who do not walk or see (2), to the way in which students with disabilities are taught that it's better to look, move, and behave as much like their nondisabled peers as possible (3), to the way in which terms associated with disability are used as insults in everyday language (4). Unlike racism or sexism, however, ableism remains, in the words of Canadian disability scholar Gregor Wolbring, "one of the most societally entrenched and accepted isms" (5). Ableism becomes systemic as patterns of discriminatory and exclusionary practices against people with disabilities are entrenched in sectors that are fundamental to societal membership, such as education, employment, and housing. Limited access and opportunities in one of these key sectors, such as education, often automatically leads to further restrictions in employment opportunities, which in turn limits housing options (6-8).

## MEDICAL ABLEISM ROOTED IN EUGENIC LOGIC

One key sector in which ableism is most deeply rooted is healthcare. Disability scholar Fiona Kumari Campbell draws a direct link between ableism and a biomedical paradigm, defining ableism as “a network of beliefs, processes and practices that produces a particular kind of self and body (the corporeal standard) that is projected as the perfect, species-typical and therefore essential and fully human. Disability then, is cast as a diminished state of being human” (9). This ableist biomedical association of disability with a diminished state of being human is central to the development and practice of eugenics. D.J. Kevles defines eugenics as the “improvement of human genetics by ensuring individuals deemed unfit in society do not breed; for example, forced sterilization, separation of communities, genetic testing of embryos in order to select for individuals without certain disorders” (10). Rosemarie Garland-Thomson thus uses the term “eugenic logic” to describe the ableist belief that “our world would be a better place if disability could be eliminated.” (11) Under the influence of such eugenic logic, medical practitioners assume that disabled people have a poor quality of life and prescribe or rule out courses of treatment accordingly. Indeed, studies have consistently shown that, as a group, health care professionals tend to substantially underestimate the quality of life of people with disabilities (12-15). Most recently, a survey of more than 700 US physicians, across several specialties, found that just over 82% reported that people with disabilities have a significantly worse quality of life than nondisabled people (16).

## COVID-19 HEALTHCARE POLICIES AS EVIDENCE OF THE GRIEVOUS AND IRREDEMIABLE ABLEISM AFFLICTING HEALTHCARE IN CANADA

The novel coronavirus, which for the better part of two years put ‘normal’ life across the planet on pause, has revealed in the starkest of terms the real and present danger that medical ableism poses for people with disabilities. Just as COVID-19 is not confined by national borders, the prevalence of medical ableism that the pandemic revealed likewise transcends geographical boundaries. As Panocchia et al. observe, “Although different countries have proposed different guidelines to manage this emergency, these proposed criteria do not sufficiently consider people living with disabilities. People living with disabilities are therefore at a higher risk of exclusion from medical treatments as physicians tend to assume they have poor quality of life” (17). In the same vein, Ignagni et al. identify a “eugenic logic” underpinning most worldwide healthcare responses to COVID-19, such as Critical Care Triage Protocols that list pre-existing disability as an exclusion criterion for receiving Critical Care in the event that the system is overwhelmed, and critical care resources need to be rationed (18).

## MAID COMPLICATED BY MEDICAL ABLEISM

Like many of the healthcare responses to COVID-19, the expansion of eligibility for MAID in Canada to include people with disabilities who are not at the end-of-life is demonstrably rooted in medical ableism. To begin with, as healthcare professionals, MAID assessors are not immune to the prevalent influence of medical ableism rooted in eugenic logic (19). This becomes particularly significant given that studies consistently demonstrate that healthcare professionals who provide care to disabled individuals are often more pessimistic and upset about their charges’ prognoses than are the affected individuals themselves (20-22). Some may argue that this is essentially a moot point because people with disabilities meet with MAID assessors only after they have already applied for MAID. However, such an argument fails to take into consideration the fact that, among other things, MAID assessors are tasked with determining “the greatest source of suffering” that is prompting a person’s request for MAID (23). MAID assessors afflicted with undiagnosed ableism are likely to automatically view the existence of disability, in and of itself, as the greatest source of suffering. They thus risk conflating suffering stemming from remediable social conditions, such as poverty and the lack of affordable, accessible housing and community-based, user-directed personal support services, with the ‘irremediable’ presence of disability.

It is important to recognize that it is not just individual MAID assessors who can perpetuate the ableist conflation of suffering caused by remediable social deprivations with the ‘irremediable’ presence of disability; rather, this ableist conflation is present within the MAID law itself. Once eligibility for MAID was expanded to include people with illnesses and disabilities whose natural death was *not* reasonably foreseeable, Canada became a country in which it is accepted that certain sorts of lives with certain limitations can be terminated with medical assistance. This means that ill and disabled Canadians, along with their families, are now routinely encountering messages telling them that, if they are experiencing X, Y, and Z because of their condition, ending their lives through MAID is a valid solution to their suffering. The prevalence of this ableist medical and social messaging is resulting in increasing numbers of ill and disabled people ‘choosing’ MAID as a final capitulation to ableism.

One casualty of such ableism was Sophia (a pseudonym), a 51-year-old Ontario woman with severe sensitivities to chemicals who ‘chose’ medically-assisted death after her desperate search for affordable housing free of cigarette smoke and chemical cleaners failed. She had Multiple Chemical Sensitivities (MCS), a chronic condition. “The government sees me as expendable trash, a complainer, useless and a pain in the ass,” Sophia said in a video filmed on Feb. 14, 2022, eight days before her death. As Avis Favaro of CTV News reported:

[Sophia] died after a frantic effort by friends, supporters and even her doctors to get her safe and affordable housing in Toronto. She also left behind letters showing a desperate two-year search for help, in which she begs local, provincial and federal officials for assistance in finding a home away from the smoke and chemicals wafting through her apartment...

Letters she wrote said that indoor cigarette and pot smoking increased, sending fumes through her Scarborough apartment building's ventilation system. More chemical cleaners were used in the hallways that worsened her symptoms. She confined herself to her bedroom – or “dungeon,” as she called it – for most of the pandemic, sealing the vents to keep cigarette and pot smoke from wafting into her unit.

Four Toronto doctors were aware of Sophia's case and they also wrote to federal housing and disability government officials on her behalf. In that letter the doctors confirmed that her symptoms improved in cleaner air environments and asked for help to find or build a chemical-free residence.

“We physicians find it UNCONSCIONABLE that no other solution is proposed to this situation other than medical assistance in dying,” they wrote. (24)

Sophia personally reached out to many Canadian disability rights advocates, including myself, for help in her desperate fight for the safe housing that would have enabled her to live. As a result, her story featured in testimony given by disability-rights advocates to the House of Commons Justice Committee studying Bill C-7 in the fall of 2020. They testified that, if Bill C-7 was passed and MAID was expanded, people like Sophia, people worn down and worn out by years of trying unsuccessfully to obtain the supports they need to live, will ultimately be left with no other option but MAID.

Sadly, it was only after her death that Sophia's story garnered any kind of public attention. But even more sad – indeed, maddening – is that when Sophia's story finally *did* generate some posthumous media attention, it prompted champions of MAID to subtly cast aspersions on the veracity of her story. For example, in a news story entitled “Are Canadians being driven to assisted suicide by poverty or healthcare crisis?” published in *The Guardian*, Leyland Cecco tells Sophia's story, and then quotes the following response by Dalhousie Law professor and MAID advocate Jocelyn Downie: “You have to meet rigorous eligibility criteria. And being poor and not having a home, or a home that is suitable for you, does not make you eligible.” (25) In other words, “There's nothing to see here, folks. Move along.”

There is a sense in which Downie's discounting of Sophia's story is unsurprising. For, even in the midst of such ongoing and growing injustices being perpetuated against people with disabilities through systemic medical ableism, the field of bioethics continues to privilege the voices of philosophers and ethicists who see the expansion of MAID within a medical system and a society that are steeped in ableism as inescapable and, ultimately, compatible with autonomy. Opposing views of the expansion of eligibility for MAID to people with disabilities who are not at the end-of-life but living in an ableist society as being detrimental to both the autonomy and well-being of people with disabilities – views most commonly expressed by disability-rights advocates – are summarily dismissed as paternalistic. A recent example of this is a paper entitled “Choosing death in unjust conditions: hope, autonomy and harm reduction,” published in the April 2023 issue of the *Journal of Medical Ethics*. In their paper, Kayla Wiebe and Amy Mullin “consider and reject arguments that the autonomy of people choosing death in the context of injustice is necessarily reduced, either by restricting their options for self-determination, through their internalisation of oppressive attitudes or by undermining their hope to the point that they despair” (26). Using what they term a “harm reduction” approach, they argue that “even though such decisions are tragic, MAID should be available” to people with disabilities who choose to die by MAID because they cannot get the support they need to live with dignity. This is because:

Rather than betraying an ‘ableist bias,’ their decisions can be more charitably and respectfully interpreted as an accurate assessment of their situation. It is one thing to identify an ableist bias in a person or a policy where there is no lived experience with a disability, and quite another to attribute ableism to a person who has intimate experience living with their disability, and to on this basis question the legitimacy of their decisions regarding their own care. (26)

Rephrased in plain language, what Wiebe and Mullin are essentially saying is, “Yeah, ableism exists, and it sucks and we should work to reduce it. But the reality is that we will never eradicate it. So, if a person with disabilities wants to get MAID to escape the crappy life they have because they live in an ableist society, we should believe them regarding how crappy their life is and let them die by MAID.” In my view, such an argument is nothing other than eugenic logic cloaked in the language of autonomy.

## CONCLUSION

The Parliamentary and Senate Committee studies of Bill C-7, the proposed expansion of eligibility for MAID, took place in the fall and winter of 2020-2021 while the entire country was under pandemic lockdown. The breathtaking irony of this situation is that, at the very time when government and public health officials were urging Canadians to take precautions and even to make sacrifices for the sake of protecting the lives of vulnerable people, some of these same government officials were working to push through a bill that would make many of these same vulnerable people eligible for a state-sanctioned death. The kind of logical and ethical contortions that this required had to be of Olympic calibre, matched only by the logical and ethical contortions that it took to quote from the UN Convention on the Rights of Persons with Disabilities in the Preamble to Bill C-7, when three UN Human Rights experts declared Canada's MAID regime to be in violation of that very Convention. In lieu of being able to organize any sort of in-person last-stand protest, since it was the middle of the pandemic, leaders in Canada's disability community organized the Disability Filibuster, a grassroots online protest on a scale never before undertaken in Canadian disability history. The idea was conceived on March 3, 2021. In the span of a mere three days, a nation-wide working

group of disability rights and equality rights activists had come aboard, seed funding was secured, extensive disability accommodations were arranged, a suitable online platform was determined, publicity was generated, and a round-the-clock, inclusive livestream protest of disabled artists, activists, scholars and allies was launched. The inaugural Filibuster broadcast began at 7 PM on March 8, 2021. After an initial invasion by Zoom bombers shortly after launch forced a sudden interruption, it resumed at 7 PM on March 9 and continued late into the night. In total, the Disability Filibuster ran live, continuous broadcasts for almost 60 hours with only brief nightly breaks between 4 AM and 6 AM EST. Content ranged from lectures, interviews and panel presentations to artistic, comedic and dramatic performances and laid-back coffeehouse late-night conversations. Each and every contribution was thematically tied to the Filibuster's central mission of stopping the passage of a dangerous amendment to Canada's assisted suicide laws, by exposing the injustice, ableism and inhumanity at its core (27).

Despite these herculean efforts by the disability community, Bill C-7 passed into law on March 17, 2021. The passing of Bill C-7, and ongoing efforts to further expand eligibility for MAID to include people with a sole diagnosis of mental illness and so-called 'mature minors' are clear and disturbing indicators that systemic and medical ableism are not just alive but thriving in Canada. Sadly, this relentless expansion of MAID will inevitably result in a growing number of Canadians with disabilities losing their lives to ableism disguised as autonomy.

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Aucun à déclarer

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#### Conflicts of Interest

None to declare

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