

Brief of the
Council of Canadians With Disabilities
to
The Standing Committee on Justice and Human Rights
regarding
Bill C-7, An Act to amend the Criminal Code
(Medical Assistance in Dying)

October 31, 2020

Introduction

We are in unprecedented times as a nation. The COVID-19 pandemic continues to threaten the lives of Canadians, as it turns our usual ways of life upside down. COVID-19 is also shining a harsh spotlight on the systemic inequities which continue to plague our society, and isolate vulnerable populations. Ironically, it is during this time of unprecedented uncertainty, when so much of our focus as a country has been on taking measures to protect the lives of our most vulnerable citizens, that this Parliamentary Justice Committee has been convened to study the potential impacts of Bill C-7, a bill which would expand eligibility for Medical Assistance in Dying (MAiD) to include anyone with an illness or disability who is experiencing physical and/or psychological suffering that is “intolerable *to them*,” regardless of whether or not they are at end-of-life. Both COVID-19 and the extensive expansion of MAiD that Bill C-7 proposes have a disproportionate, detrimental impact on people with disabilities. This is because Canada suffers from a pre-existing condition that has plagued our country since long before the advent of COVID-19. The name of this condition is ableism.

What is Ableism?

Disability scholar, Veronica Chouinard, defines ableism as “ideas, practices, institutions and social relations that presume ablebodiedness, and by so doing, construct persons with disabilities as marginalised ... and largely invisible `others.’”¹ 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.² 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

¹ V. Chouinard, “Making Space for Disabling Difference: Challenges Ableist Geographies,” *Environment and Planning D: Society and Space* 15 (1997): 379–387.

² Ashley Eisenmenger, “Ableism 101 - What Is Ableism? What Does It Look Like?,” *Access Living* (blog), December 12, 2019, <https://www.accessliving.org/newsroom/blog/ableism-101/>.

walk or see,³ 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,⁴ to the way in which terms associated with disability are used as insults in common parlance.⁵ 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."⁶

Types of Ableism

Just as other forms of discrimination, like sexism or racism, operate on interpersonal, internal, and systemic levels, there are also interpersonal, internalized, and systemic forms of ableism.

Interpersonal ableism can most basically be defined as an act of disability-based discrimination that a nondisabled person carries out against a person with disabilities in a one-on-one context. A parent refusing to move his/her child's birthday party to an accessible venue so that the child's classmate, who uses a motorized wheelchair, could attend would be considered an instance of interpersonal ableism.

Internalized ableism can be defined as the process by which a disabled person absorbs the ableist attitudes that nondisabled people have repeatedly exhibited towards him/her, and begins to believe that his/her disabilities *actually do* make him/her inferior to nondisabled people. Many people with disabilities experience internalized ableism, either episodically or consistently throughout their lives.⁷ In her seminal book, *Contours of Ableism*, disability scholar, Fiona Kumari Campbell, describes the phenomenon of internalized ableism in the following terms, "From the moment a child is born, he/she

³ Kathy Livingston, "When Architecture Disables: Teaching Undergraduates to Perceive Ableism in the Built Environment," *Teaching Sociology* 28, no. 3 (2000): 182–91, <https://doi.org/10.2307/1318988>.

⁴ Thomas Hehir, "Eliminating Ableism in Education," *Harvard Educational Review* 72, no. 1 (April 1, 2002): 1–33, <https://doi.org/10.17763/haer.72.1.03866528702g2105>.

⁵ J Aaron, "Forever Crooked: How Everyday Language Reflects Negative Attitudes about the Physically Disabled.," *The Conversation* (blog), May 11, 2015, <http://theconversation.com/forever-crooked-how-everyday-language-reflects-negative-attitudes-about-the-physically-disabled-38881>.

⁶ Gregor Wolbring, "The Politics of Ableism," *Development* 51, no. 2 (2008): 252–58.

⁷ Fiona A. Kumari Campbell, "Exploring Internalized Ableism Using Critical Race Theory," *Disability & Society* 23, no. 2 (March 1, 2008): 151–62, <https://doi.org/10.1080/09687590701841190>.

emerges into a world where he/she receives messages that to be disabled is to be *less than*, a world where disability may be *tolerated* but in the final *instance*, is *inherently negative*. We are all, regardless of our status, shaped and formed by the politics of ableism.”⁸ Campbell goes on to draw parallels between internalized ableism and internalized racism. She notes that, like internalized racism, internalized ableism inculcates shame regarding one’s identity and abilities, generates a mindset that disability makes a person inferior to the nondisabled population, and discourages any kind of association with other disabled people for fear of acquiring greater stigma.

Systemic ableism can be defined as patterns of discriminatory and exclusionary practices against people with disabilities which become entrenched in sectors which are fundamental to societal membership, sectors 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. Ableism thus becomes systemic.

In recent weeks and months, horrific acts of violence and abuse against racialized people who were in distress have forced Canadians to begin to wake up to the reality of enduring systemic racism in Canada. Without in any way subtracting or distracting from the huge and urgent need to address systemic racism in Canada, the fact that our country is on the verge of expanding eligibility for Medical Aid in Dying to include people with disabilities who are not at end-of-life creates an equally huge and urgent need for Canadians to wake up to the reality and the impacts of enduring systemic ableism in Canada.

⁸ Fiona K. Campbell, *Contours of Ableism: The Production of Disability and Aabledness*, vol. 17 (London: Palgrave Macmillan, 2009), <https://doi.org/10.1080/09687590701841190>.

Systemic Ableism and COVID-19 – Double Jeopardy for Canadians with Disabilities

The COVID-19 pandemic has laid bare the systemic ableism that relegates people with disabilities to the margins of both society and healthcare. Running contrary to the oft-repeated public health mantra of “We’re all in this together” have been stories of COVID-19 outbreaks in long-term care facilities and group homes causing personal support workers and health care aides to fall ill themselves, and prompting those who remained to abandon their elderly and disabled clients. Interestingly, and tellingly, while the deplorable conditions of seniors languishing in long-term care facilities has (rightfully) garnered national attention, the abandonment of physically and developmentally disabled adults by staff at Participation House, a care home in Markham, Ontario, in April, was little more than a blip in the 24-hour news cycle.⁹ ¹⁰or both the mainstream media and the general public, there appears to be a clear qualitative distinction between the physically and developmentally disabled residents of Participation House and the (mostly) senior residents living in long-term care facilities.

And yet, data from the 2016 Census indicates that there were 11,320 people with disabilities and under age 65 living in nursing homes in 2015.¹¹ The nursing homes that elderly and disabled people live in are often unsanitary, in poor repair, understaffed and subject to high staff turnover rates. Nursing homes also restrict the choices available to residents, and may have policies that amount to inhumane treatment. Meal, wake-up and bed-times are set based on facility schedules, baths may be limited¹², and toilet

⁹ Chris Fox, “Two More Residents Die at Participation House in Markham, Bringing COVID-19 Death Toll to Six,” thestar.com, April 28, 2020, <https://www.thestar.com/news/gta/2020/04/28/fifth-covid-19-resident-death-at-participation-house-in-markham.html>.

¹⁰ Katherine Declerq, “‘I Saw the Fear in Their Eyes,’ Former MP Says of Residents at Ont. Facility for Vulnerable Adults,” Toronto, May 1, 2020, <https://toronto.ctvnews.ca/i-saw-the-fear-in-their-eyes-former-mp-says-of-residents-at-ont-facility-for-vulnerable-adults-1.4920784>.

¹¹ Statistics Canada, *Data on Collective Dwellings from the 2016 Canadian Census*, 2016, <https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/dt-td/Rp-eng.cfm>.

¹² Harold Gagné, “Se Battre Pour Avoir Droit à Des Bains En CHSLD,” Le Journal de Montréal, July 3, 2017, <https://www.journaldemontreal.com/2017/07/03/se-battre-pour-avoir-le-droit-a-des-bains-en-chsld-1>.

paper or adult diapers may be rationed.¹³ And, in the wake of the pandemic, even more restrictions are now in place. The limitations of institutional life increase the probability of physical, emotional, and financial abuse or neglect.¹⁴

Ableism and Suicidality – The Double-Standard Facing People with Disabilities

Ableism creates a disparity in societal reactions to suicidal behaviour based on a person's disability status.¹⁵ When a non-disabled person is suicidal, they are directed towards suicide prevention resources. On the other hand, suicide is assumed to be a “rational” choice for a person with a disability – solely because a disability is present.¹⁶ People with disabilities are at a higher risk of suicide, yet they face substantial barriers when trying to access suicide prevention services.¹⁷ Medical professionals overlook typical sources of stress; problems arising from relationship breakdowns, depression, and isolation are wrongly attributed to disability.^{18, 19} Suicide prevention measures should be applied equally to all people.

Due to the phenomenon of internalized ableism, it is highly likely that the removal of “reasonably foreseeable” natural death as a limiting eligibility criterion for the provision of MAID will result in some people with disabilities seeking MAID as an ultimate capitulation to a lifetime of ableist oppression. In a study of 222 disability pensioners with mental illness, Oexle and colleagues found that “Higher baseline self-stigma predicted suicidal ideation both at baseline and longitudinally, providing first evidence of

¹³ Charles Lacavalier, “Quotas of Diapers in CHSLDs? | The Journal of Quebec,” *Le Journal de Quebec*, November 10, 2016, <https://www.journaldequebec.com/2016/11/10/quotas-de-couches-dans-les-chsld>.

¹⁴ Lori Post et al., “Elder Abuse in Long-Term Care: Types, Patterns, and Risk Factors,” *Research on Aging* 32 (April 20, 2010): 323–48, <https://doi.org/10.1177/0164027509357705>.

¹⁵ Beth Haller and Sue Ralph, “Not Worth Keeping Alive? News Framing of Physician-Assisted Suicide in the United States and Great Britain,” *Journalism Studies* 2, no. 3 (2001): 407–21.

¹⁶ David C. Clark, “Rational Suicide and People with Terminal Conditions or Disabilities,” *Issues L. & Med.* 8 (1992): 147.

¹⁷ Carol J Gill, “Suicide Intervention for People with Disabilities: A Lesson in Inequality,” *Issues L. & Med.* 8 (1992): 37.

¹⁸ Diane Coleman, “Assisted Suicide Laws Create Discriminatory Double Standard for Who Gets Suicide Prevention and Who Gets Suicide Assistance: Not Dead Yet Responds to Autonomy, Inc.,” *Disability and Health Journal* 3, no. 1 (2010): 39–50.

¹⁹ Lynne Pearce, “Learning Disability and Mental Health,” *Mental Health Practice (2014+)* 20, no. 6 (2017): 10.

a longitudinal and potentially causal relationship. These results also imply that self-stigma has a long-lasting effect on suicidality.”²⁰ While there is much research linking self-stigma with suicidality in other minority groups, such as the LGBTQ community²¹ and racialized people,²² there is still a dearth of research examining what connection, if any, exists between perceived ableism and suicidality among people with disabilities. This may, itself, be seen as evidence of the pervasiveness of ableism.

Recommended Amendments aimed at Preventing Bill C-7 from Weaponizing Ableism in Canada

Given the demonstrated ongoing prevalence of ableism in Canada, the Council of Canadians with Disabilities is recommending the following amendments to Bill C-7 in hopes of limiting the Bill’s capacity to weaponize ableism in this country:

Recommendation #1: Any ill or disabled person who indicates that their intolerable suffering stems from inadequate housing, personal care, income support, or palliative care should be assigned an advocate to assist them in engaging in intensive lobbying of municipal and provincial authorities to obtain the supports that they need. **Receipt of adequate housing, income support, palliative care and home-based services should be prerequisite eligibility requirements for MAiD.**

Recommendation #2: **Refer to the Supreme Court of Canada, by way of constitutional reference, Bill C-14’s existing protections limiting MAiD to cases where a person’s natural death is reasonably foreseeable.**

²⁰ N. Oexle et al., “Self-Stigma and Suicidality: A Longitudinal Study. *European Archives of Psychiatry and Clinical Neuroscience*, vol. 267, 4, 2017.

²¹ M. Luke et al., *LGBTQI+ Youth Development. Affirmative Counseling with LGBTQI+ People*, 2017.

²² R.L. Walker et al., “Perceived Racism and Suicide Ideation: Mediating Role of Depression but Moderating Role of Religiosity among African American Adults,” *Suicide and Life-Threatening Behavior* 44, no. 5 (2014): 548–559.

- Recommendation #3:** Any changes to Canada’s MAiD law must meaningfully respond to last year’s End of Mission Statement of the United Nations Special Rapporteur on the rights of persons with disabilities, wherein Ms. Catalina Devandas-Aguilar communicated her serious concerns about “significant shortcomings” in the way all levels of Canadian government “respect, protect and fulfill the rights of persons with disabilities”.²³ Specifically, Ms. Devandas-Aguilar noted that there was a lack of protocol to “demonstrate that persons with disabilities have been provided with viable alternatives when eligible for assistive dying” and that she had received “worrisome claims about persons with disabilities in institutions being pressured to seek medical assistance in dying, and practitioners not formally reporting cases involving persons with disabilities.”
- Recommendation #4:** Investigate the “worrisome claims about persons with disabilities in institutions being pressured to seek medical assistance in dying, and practitioners not formally reporting cases involving persons with disabilities”, which were identified in the UN Special Rapporteur’s report, and establish an independent body, whose membership must include representatives of the disability community, to investigate such cases moving forward.
- Recommendation #5:** Canada’s amended Medical Assistance in Dying law should follow the judicial directive of the SCC in *Carter*, which required “a carefully-designed system” that “imposes *stringent limits*” that are “*scrupulously monitored and enforced.*”

²³ Catalina Devandas-Aguilar, “OHCHR | End of Mission Statement by the United Nations Special Rapporteur on the Rights of Persons with Disabilities, Ms. Catalina Devandas-Aguilar, on Her Visit to Canada,” April 12, 2019, <https://www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=24481&LangID=E>.

- Recommendation #6:** Remove Bill C-7’s provision allowing a disabled person’s healthcare or personal care provider to be an eligible witness to that person’s request for MAiD.
- Recommendation #7:** Retain Bill C-14’s mandatory 10-day waiting period requirement, as it currently stands, and the requirement for independent verification of all MAiD requests by two witnesses.
- Recommendation #8:** In response to the prevalence of medical ableism, add language to Bill C-7 that will ensure that all discussions surrounding MAiD are patient-led and not prematurely initiated by the physician.
- Recommendation #9:** Retain Bill C-14’s mandatory 10-day waiting period requirement, as it currently stands, and the requirement for independent verification of all MAiD requests by two witnesses.
- Recommendation #10:** Remove Bill C-7’s provisions waiving Bill C-14’s important and necessary “final consent” requirements.

Conclusion

The reality of enduring systemic ableism in Canada means that Bill C-7, in its current form, will enshrine a lethal form of ableism into Canadian law by making Medical Assistance in Dying a legally-sanctioned substitute for the provision of community-based disability supports to assist people with disabilities to live. The Council of Canadians with Disabilities, along with the entire disability-rights community in Canada, is therefore pleading with policymakers to re-think and revise Bill C-7 in light of the reality of systemic ableism, and work to ensure that MAiD will not become, in effect, the weaponization of systemic ableism in Canada.

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