

VOICES FROM THE MARGINS



"I am concerned about the impact on vulnerable people and how society views and values their lives."

"There is no combination of "alternative" safeguards which can replace an end of life requirement - removal of this will be challenged via the Charter, and it will be in violation of the UN CRPD. Having 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."

"Canada needs an end of life criterion in its medical assistance in dying legislation in order to protect the equality rights of persons with disabilities. There is no combination of alternative safeguards which can replace an end of life requirement. When medical assistance in dying is provided to those who are not dying, having a disability can become a key reason for access, marking a life with a disability as a life worse than death."

"If MAiD is available to people who are not dying, it opens the door to disability as a grounds for access and shows that our society sees the lives of people with disabilities as less-valuable than those of other Canadians."

"Alternative safeguards cannot replace an end of life requirement. Removal of the end of life criterion will be in violation of the UN CRPD."

CONCERN: FAIRNESS AND EQUALITY

Many people with disabilities have serious concerns about Bill C-7. So do their friends, families, and allies. Together, we told Canada why medical assistance in dying needs to be restricted to end of life. However, the voices of this minority group were drowned out by the masses. Some of us have kept a record of our federal consultation survey responses. Here is what we had to say about fairness and equality.

If we learn from other jurisdictions the have opened medical assistance in dying where death is not reasonable foreseeable, people with disabilities are accessing assisted death at alarming and disproportionate rates."

"I am worried that people with disabilities could be seen as less worthy of life , or to have inherently less quality of life than non - disabled folks, consciously or not, by those around them including service providers, family members and physicians and that these attitudes and biases could affect decision making on the part of all parties involved."

"Of all principles, the right to live is paramount, no matter the severity of disability. That right can be protected only by the "end of life" criterion."

"This most disappointing part of the Truchon decision is that it gutted the objective of preventing stigma and promoting the substantive equality of persons with disabilities... Canada should...articulate that [the end of life criterion] exists to promote the substantive equality of persons with disabilities and send for a Supreme Court reference. "

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"If natural death is not reasonably foreseeable, then we are dealing with suicide, not 'MAiD.'"

"The end-of-life requirement should not be removed. If the requirement for reasonably foreseeable natural death is removed, the social norms of preserving life and preventing suicide will effectively be waived for people who are disabled, frail or ill."

"Loosening the current law would be dangerous in my opinion. Instead, more effort should be given to suicide prevention, not facilitating access to MAiD."

"There is no safeguard, and no combination of safeguards, that can ameliorate the devastating effect of the breach of equality rights that the government appears to be moving toward. Our government has already breached the norms of democracy by failing to respect the Caretaker Convention, and unilaterally deciding, during an election period, not to appeal the Quebec court decision. You will be changing the fundamental nature of MAiD, so that it is no longer strictly an option for persons who are dying to decide precisely how and when they will die. Now instead, you will be legalizing a procedure for a particular class of persons who are living to decide to die. This is a gross violation of our social norms of respect for life and suicide protection."

CONCERN: SUICIDE PREVENTION

Many people with disabilities, their friends, families, and allies are concerned about having equal access to suicide prevention. Without an end of life criterion in place, people with disabilities who have life left to live will be able to end their own lives with assistance because they no longer want to live. Here is what this minority group had to say about MAiD and suicide prevention in Canada's online consultations.

"I strongly support the views articulated in the Vulnerable Persons Standard, especially the expression that, 'Vulnerable persons who request physician-assisted dying may be motivated by a range of factors unrelated to their medical condition or prognosis. Canadians living with severe disabilities, mental illness and dementia, as well as seniors living in long term care are among those who may be more vulnerable to stigma, abuse, coercion, isolation and depression. Consequently, they may be more inclined to suicidal ideation, intent and behaviour.' Therefore, I deeply believe the current requirement for a 'reasonably foreseeable natural death' needs to remain foundational to the law governing MAiD."

"I am terrified and insulted for suicidal loved ones."

"I have a deep concern that this just opens the field for suicide being sanctioned"

"We need to recognize that loneliness and the feeling of being a burden are common pressures to take one's life."

"Expanding access is called for in the name of personal choice and autonomy, but MAiD was intended to provide autonomy at the end of life in situations of extreme and intolerable suffering. It was never meant to be an answer to suffering in society more generally. That should be addressed by identifying where the social determinants of health are lacking or absent in populations and communities across Canada. MAiD should not become a fallback intervention for the failure of governments to address these gaps. That is what will happen if access to MAiD is extended beyond end of life."

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"Opening up MAID to people who are not dying poses significant risk to the lives of people with a disability. Throughout history, people with various types of disabilities have been devalued to the point that their deaths have been advanced and promoted within our health care and other systems. I was personally involved with 2 such situations a few years ago which left me shocked and saddened that people could be so vulnerable in spite of our rights to equality for all people."

"Adequate health and social support services must be improved and made available to all, BEFORE making assisted dying available to all."

"'External pressure' must include social and economic factors, such as lack of palliative care or forced institutionalization. Person should receive peer counseling from someone living successfully with the same conditions."

"An abundance of research has shown that health professionals hold negative attitudes towards disability and dependence, and are quick to judge disabled people as having a "poor" quality of life. At a minimum, all professionals involved in MAiD should have extensive training to mitigate these deep biases. But my view is this will not be adequate and Canada should not be going down this slippery slope."

"In a country where so many Canadians do not have access to quality palliative care or sufficient social, income and health benefits, it is unthinkable to broaden MAiD in this way."

CONCERN: VULNERABILITY

People with disabilities and their families, friends, and allies are worried about what leads a person who is not dying to want to die. Here are some quotes pulled from our consultation responses. While those who resist the expansion of medical assistance in dying are a subset of the population, it is very important that we don't lose track of the perspectives of those who will be impacted most. It's about time that Canada respond to the voices from the margins.

"As a family physician specializing in care of persons who are elderly and persons with intellectual and developmental disabilities, I think no set of safeguards or other regulations could adequately address risks to such persons when eligibility for MAID is extended to those not near death. This is because these risks pertain to complexities and uncertainties inherent in assessing decision-making capacity and vulnerability, and because ableist and ageist attitudes in society regarding persons living with disabling conditions are difficult to eradicate. When the risk of harm is high (irreversible death), the only legislation that makes sense is to hold the line on eligibility for MAID, not to extend it."

"Abuse, pressure, and misuse already exists in the few years since Carter, both in cases in which death is truly reasonably foreseeable, and in cases in which the criterion of death being reasonably foreseeable is even now being applied in an overly broad manner."

"Canada needs to put in place a system of thorough data collection so that policymakers will become aware of all the social, economic, personal/emotional/psychological factors that make someone request MAID."

"In the past, the Government has used the laws to perpetuate abuses against minorities. It is out of the question that we should, in the future, give them any opportunity to weaponize medical institutions against vulnerable people."

A note on approach:

From January 13-27, 2020, the Government of Canada hosted an online public consultation on expanding access to medical assistance in dying. During this consultation period, an informal ask went out to a small group of supporters of the Vulnerable Persons Standard (VPS) : to submit a copy of individuals' survey responses in PDF format for analysis.

Of the more than 300, 000 responses received by the Federal Government, advisors to the VPS received copies of 60 submissions.

The text from the open-ended responses captured in these submissions were organized by theme, and the snippets displayed above were chosen to represent trending concerns from the margins of popular opinion. For more on the significance of data from the margins, see Catherine Frazee's VPS blog post titled " Medical assistance in dying, public confidence and the lesson of the driverless car."