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I appreciate the invitation to present today as part of this parliamentary review. In this polarized debate, where some frame all concerns about MAID as religion-based, let me first firmly state that my approach is based on human rights, the respect for the equal rights and dignity of persons who are ill, elderly and disabled, and the recognition of the state's duty to protect against premature death. It is informed by decades of work on professional regulation, health governance, health and human rights; and end-of-life law.

A review of this new practice is from a health governance perspective laudable. Unfortunately, Parliament put the cart before the horse by expanding the law prior to a serious evaluation of our current practice. Imagine that we decide to allow a novel form of germ-line gene-therapy for serious, untreatable conditions. But prior to undertaking a legislatively mandated five-year solid review of the risk/benefit ratio, we introduce it as a standard form of therapy, largely available on demand. This is what we are facing here.

I therefore have concerns about this review, and particularly about the premise from which it will start. In any area of policy making, it is harder to scale back a practice once there is an official professed confidence in it. It is also hard to change behaviour and expectations once a procedure is promoted and normalized; and to design post-factum structures to uncover problems and identify lacunae, particularly when a practice leaves so much flexibility, and relies heavily on the integrity of professionals committed to the practice.

I urge the committee to take a step back, and remember how the BC Supreme Court in Carter, which lies at the foundation of our current practice, stated with references to choice and best interest of the patient that "if it is ever ethical… for a physician to assist in death, it would be only in limited and exceptional circumstances… The concern about imposing stringent limits stems from the consensus that unlimited physician-assisted death would pose serious risks" (Carter vs. Canada).

The Committee should be willing to question whether our current practice respects this, and what even further expansion would mean. It should do more than review the statistical self-reported data and the limited analyses that have been undertaken. It should take the time to listen to family members who have had bad experiences with rushed MAID of loved one's; to people who are already struggling in our health care and social support system, particularly during the pandemic, and for whom offers of MAID are often perceived as a threat to their well-being. The committee should hear from Jonathan Marchand, a man with ALS who complained before the Senate about his lack of health care choices; from the family members of Chris Gladders who received MAID in shockingly dehumanizing squalid circumstances; from Roger Foley who was offered MAID instead of access to good care; from the family of Alan Nichols, and about other more recent cases that are emerging. It should take seriously the voices of people with disabilities who experience the explicit promotion of MAID as a confirmation that our society prioritizes ending their life rather than providing adequate support and care.

I urge you to be imaginative and ask the question how our societal and legal endorsement of a broad MAID practice may already be impacting on what we think our elderly, and people with disabilities should do when they struggle and solutions to their suffering are complex and not immediately forthcoming; and how this will impact how they themselves think about what they should be doing when faced with old age, fragility and disability. I urge you to keep in mind the challenging health issues Indigenous people and racialized Canadians disproportionally face; the revolting situation in many of our elderly and long-term care homes exposed during the pandemic; and the lack of choices for elderly and people with disabilities. Think about that when exploring the risks of normalizing MAID as therapy for suffering; and when critically analyzing the premise in our MAID law that capacity and informed consent procedures are sufficient protection against abuse in this context.

Many of these concerns about the impact of ableism are particularly long-term. But I mentioned already concrete examples of current concerns. How common are these? I suggest we need more robust data.

The first Health Canada MAID report should be a wake-up call. In addition to showing the normalization of MAID through the rapid uptake, particularly in some provinces (faster than in, for example, Belgium & the Netherlands, two countries with significantly more investment in palliative care and social support), the report confirms some of the concerns with our already broader than strict end-of-life practice. It documents, for example, various factors associated with 'unbearable suffering' that lie at the basis of the more than 15,000 MAID requests: it includes fear for being a burden to family, friend and caregivers (34%); loneliness (14%); 53% identified "loss of dignity"--a concept profoundly influenced by ableist perceptions that our MAID practice may stimulate; inadequate pain control (or fear for that): 54%—thus reflecting possible lack of access to adequate health care and palliative care; and even in some cases existential suffering.

In the question period and in a more detailed memo I will be happy to elaborate on why this reflects, in my view, that we are already beyond a practice that can be exceptionally justified when it clearly reflects the best interest of the patient. We seem to have abandoned the more precautionary approach that arguably was still emphasized as of key importance in the Carter decision. I hope this precautionary approach will be taken more seriously in this review.

References

Carter v. Canada (Attorney General), 2012 BCSC 886, [2012] B.C.J. No. 1196 (QL), para. 342.