

Testimony to the *Commission des relations avec les citoyens* sur le projet de loi n° 11, Loi modifiant la Loi concernant les soins de fin de vie et d'autres dispositions législatives.

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Thank you for this opportunity to speak with you today on this critical issue. I am pleased to see that Quebec has taken a measured and reasonable approach to the issue of MAiD for mental illness which remains a highly contested issue and as such warrants the caution which Quebec has shown on this issue. I will add a few comments to what my colleague has just presented, primarily about people with intellectual and developmental disabilities. Before I do I have a couple of general comments to add regarding advanced request for MAiD.

First, I am concerned that should Quebec move forward on advance directives, that there is no timeframe or renewal schedule included in the Bill. People can and do change their minds regarding euthanasia, particularly at the time when the actual acute suffering is experienced. Currently advance health care directives are often made well in advance of when they may be required and can be forgotten over time or people's preferences change. Given the finality of MAiD it would seem prudent to ensure the advance directive is as recent as possible. This can only be achieved if a frequent renewal and confirmation process is required such as an annual reconfirmation process.

I am also concerned that persons may indicate in a general advance directive that they wish to have MAiD should they experience onset of severe dementia or if they experience a severe traumatic event resulting in brain injury or physical disabilities such as para or quadriplegia. It is well documented that many people will contemplate suicide post injury but that this tends to dissipate after a period of adjustment and many subsequently report a quality of life on par with non-disabled persons. Further, it is also well established that non-disabled persons rate the quality of life for disabled persons much lower than disabled persons themselves do- this is known as the *disability paradox*.¹ My concern is if an advance request for MAiD exists and a person is unable to communicate their current will and preference, perhaps temporarily due to a coma for example, action will be taken to end their life based on the prior advance directive when the person may well have gone on to a life of meaning and quality. While the current act may mitigate against this to some degree, once advance requests are established, it is a small step to these being broadened to situations such as traumatic injury.

My concerns regarding persons with intellectual disabilities relate more to what the current Bill may lead to rather than its direct impact. Many persons tend to assume people with IDD will not be at risk due to their inability to consent. The reality is however that many people with IDD are capable of giving consent and indeed a strict interpretation of Article 12 of the CRPD would affirm their right to do so and the right

¹ Angner, E., Ray MN., Saag, KG., & Allison, J J. (2009). Health and Happiness among Older Adults: A Community-based Study. *Journal of Health Psychology* 14, no. 4 503-512; Erosa NA, Berry JW, Elliott TR, Underhill AT, Fine PR. (2014) Predicting quality of life 5 years after medical discharge for traumatic spinal cord injury. *British Journal of Health Psychology*. 19(4):688-700. doi: 10.1111/bjhp.12063. Epub 2013 Aug 9. PMID: 23927522; Albrecht, G. L. and P. J. Devlieger. (1999) The disability paradox: high quality of life against all odds. *Social Science & Medicine*, 48: 977-988.

for trusted others to assist them in expressing their will and preference. Tuffrey-Wijne et al. (2018; 2019) have documented numerous cases of people with IDD being euthanized in the Netherlands and have raised serious concerns regarding how the consent and capacity determinations were handled in many of these cases.²

With the introduction of advance directives, a level of substituted judgement is inevitably introduced as no contemporaneous consent will be possible at the time of the assisted death. Indeed this is the whole point of advance directives. With this weakening of direct consent and the introduction of a level of substituted judgement, it is a small step to allowing those who are legal decision makers or supporters to consent to MAiD on a person with IDD's behalf.

I worry that we will soon see calls for legalizing the killing of disabled people who are unable to formally consent, at the request of their parents or guardians. As MAiD regimes expand to include those with cognitive impairments and move away from explicit contemporaneous consent through vehicles like advance directives, it is not beyond imagining that guardians and parents may be extended the right to consent on behalf of their disabled children. Indeed we already have calls for euthanasia to be legalized for disabled infants as it currently is in the Netherlands.³ Even when clearly illegal under current laws we are seeing reports of doctors suggesting MAiD to parents of adult children with IDD.⁴ The all too prevalent filicide of disabled children and the rather sympathetic response such cases often garner, being framed as 'mercy killings', suggests there would be significant public support for the practice.⁵ It is also not inconceivable that families with decision-making control or influence will choose MAiD for their children when faced with insurmountable barriers to securing appropriate supports just as we are seeing disabled people currently choosing MAiD due to a lack of appropriate supports.⁶

² Tuffrey-Wijne I, Curfs L, Finlay I, Hollins S. (2018). Euthanasia and assisted suicide for people with an intellectual disability and/or autism spectrum disorder: an examination of nine relevant euthanasia cases in the Netherlands (2012-2016). *BMC Medical Ethics*.19(1):17. doi: 10.1186/s12910-018-0257-6; Tuffrey-Wijne I, Curfs L, Finlay I, Hollins S. (2019) "Because of his intellectual disability, he couldn't cope." Is euthanasia the answer? *Journal of Policy and Practice in Intellectual and Developmental Disabilities*, 16: 113-116. doi:[10.1111/jppi.12307](https://doi.org/10.1111/jppi.12307).

³ <https://nationalpost.com/news/canada/canada-maid-medical-assistance-in-dying-children>; Verhagen E, Sauer PJ. (2005). The Groningen Protocol — euthanasia in severely ill newborns. *English Journal of Medicine*.; 352(10), 959-96.

⁴ <https://www.cbc.ca/news/canada/newfoundland-labrador/doctor-suggested-assisted-suicide-daughter-mother-1.4218669>

⁵ See for example: Picciuto, E. (2014, November 4). U.K courts grant mother right to end her 12-year-old disabled daughter's life. *The Daily Beast*; Perry, D. (2017) *On media coverage of the murder of people with disabilities by their caregivers*. Rudderman Foundation; Joni Eareckson Tada 'Disappointed in Dr. Phil'. *Huffpost* 06/27/2012 06:01pm EDT. https://www.huffpost.com/entry/disappointed-in-dr-phil_b_1546354; Coorg, R. & Tournay, A. (2012) Filicide-Suicide Involving Children With Disabilities. *Journal of Child Neurology* 28(6) 745-751.

⁶ See for example: "Easier to let go" without support: B.C. woman approved for medically assisted death speaks out. (2022, June 7). British Columbia. <https://bc.ctvnews.ca/easier-to-let-go-without-support-b-c-woman-approved-for-medically-assisted-death-speaks-out-1.5937496>; *The disabled are choosing to die because they can't afford to live*. (n.d.). *www.ipolitics.ca*. Retrieved June 14, 2022, from <https://www.ipolitics.ca/news/the-disabled-are-choosing-to-die-because-they-cant-afford-to-live>.

If we continue to weaken the need for direct consent through permitting advance directives and allowing for neonates and children to be euthanized, it is a very small step to involuntary euthanasia of disabled people considered unable to consent.