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Brief to the Commission Spéciale sur l'évolution de la Loi concernant les soins fin de vie

National Assembly of Quebec

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I would like to thank the Commission for this opportunity to speak with you and for the thoughtful approach that is being taken with regards to the evolution of the Act respecting end of life care. My particular expertise is in the area of disability with a particular focus on intellectual and developmental disability. I have extensive experience in disability policy and support service design and delivery. I have studied ethical issues related disability including extensive work on assisted suicide and euthanasia. I was a member of the federally commissioned expert review of MAiD undertaken by the Council of Canadian Academies, serving on the Advance Directives working group. I am also the parent of a young adult with an intellectual disability. My primary expertise is with the federal MAiD regime so I will reference that rather than Quebec law and practice. My presentation will focus on the vulnerability of people with disabilities within the evolving MAiD regime in Canada.

As the Commissioners will be aware, there has been a great deal of concern within the disability community with regards to MAiD. The recent federal changes to MAiD eligibility was strongly opposed by the disability community with over 140 Canadian disability rights groups and allies signing a letter outlining their concerns.¹ Their concern is shared by the UN Special Rapporteur on the rights of persons with disabilities Devandas-Aguilar who, after her visit to Canada, was “extremely concerned” about the implications of assisted dying legislation on people with disabilities after hearing multiple complaints. In her report she states: “I urge the federal government to investigate these complaints and put into place adequate safeguards to ensure that persons with disabilities do not request assistive dying simply because of the absence of community-based alternatives and palliative care.”² Similar concerns were raised by her successor Gerard Quinn during his testimony to the recent Senate committee reviewing Bill C7.³ He was joined in his concern by the Independent Expert on the Enjoyment of all Human Rights by Older Persons and, the Special Rapporteur on Extreme Poverty and Human Rights.⁴ Despite this, Bill C7 not only passed but was expanded beyond its original purpose of removing the reasonable foreseeability requirement to included mental illness within two years with little or no study or consultation. It is difficult to imagine a scenario where a piece of legislation directly impacting another equity seeking group that was near universally opposed by members of that group and UN rights watchdogs even getting to the floor of the house letting alone passing with a solid majority. In light of this it is not hard to see why the disability community feels their concerns have been ignored throughout the evolution of MAiD, this despite the fact they are the only group named as being eligible simply by membership in the disability community. In this brief I will outline some of the key concerns of the disability community in general and then briefly consider specific risks to people with intellectual and developmental disabilities.

MAiD AS A SUBSTITUTE FOR ACCEPTABLE DISABILITY SUPPORTS

There have now been a number of cases that seem to support the concern that people with disabilities are opting for MAiD rather than live a life they consider dehumanizing and incompatible with a life of meaning and quality.⁵ Archie Rolland died by AD in 2016. A press

report at the time noted: 'It's not the illness that's killing him, Rolland said in a series of emails with the Montreal Gazette. He's tired of fighting for compassionate care'.⁶ M. Truchon plaintiff in the Quebec judgement declaring the reasonable foreseeability requirement unconstitutional also noted it is the nature of the care he is being offered which is, at least in part, behind his suffering: 'At a news conference... Mr. Truchon had an assistant read a statement explaining that he couldn't face the prospect of life confined to an institution'.⁷

41 year old Sean Tagert, a man with ALS, died by MAiD in August of 2019. He was quite explicit that his reason for choosing assisted death was his inability to secure sufficient home care funding in order live a life he considered worth living.⁸ All he wanted was to remain in his home which had the necessary adaptations and to be able to spend time with his young son in their home.

The testimony of Québécois Jonathan Marchand to the Senate Standing Committee on Legal and Constitutional Affairs powerfully sums up the situation many disabled persons find themselves confronted with: :

I was prepared to do anything to get out of this medical hell, but just like Jean Truchon, I was denied the home care support that I needed. I complained to the highest instances. I was told that it was a political issue as living in the community with the necessary support is not a right in Canada. After two and a half years in the hospital, I ended up in a long-term care facility.... I gave up and sank into depression. I was ashamed to live in this ghetto. Without humanity and freedom, life no longer has any meaning. I regretted having refused euthanasia. I simply wanted to live with my partner, work and have a normal social life. I wanted to die. ... I discovered that about 70% of people with severe disabilities live in institutions in Quebec. The others cling to living at home, but often find themselves also isolated. Many have committed suicide or have accepted euthanasia to avoid suffering my fate. My disability is not the cause of my suffering, but rather the lack of adequate support, accessibility, and the discrimination I endure every day....Why is it so hard to be seen and heard when we want to live?⁹

2016 census data reports over 18,355 people between the ages of 18 and 64 living in health care and related facilities in Quebec and some 4945 in nursing home and seniors facilities including 1325 under the age of 50.¹⁰ The failings of our long term care system is well document but has been emphasized during the current pandemic. Even in the best of circumstances these are not suitable homes for younger people with disabilities. Overall, best practice in the field strongly supports maximum independence and control over disability supports through direct funding and home based supports. There is no reason inherent to their disability that anyone with a disability cannot be supported in a suitably adapted home. The reason younger people are institutionalized is largely structural based not on best practice or the needs of the individual but

on outdated policy and financial constraints. Overwhelmingly disabled people have indicated their strong preference to remain in their own homes and communities and to have control over their supports.¹¹ Access to community supports, even if sufficient supports are available, is usually met with significant delays.¹² Even with regards to basic aids and devices, over 1.5 million persons with disabilities in Canada aged 15 years and over, had an unmet need for an aid or device. Of these, 1 million indicated that cost was the reason for their unmet need.¹³

While many of the MAiD related cases are concerned with inappropriate institutionalization as the source of suffering, those not faced with this choice at the moment struggle against multiple socio-economic barriers. Income levels of those with more severe disabilities were less than half of the population without disabilities with 28.6 working age adults with disabilities living in poverty compared to 10% of the general population.¹⁴ Suicide and suicidal ideation are strongly correlated with socio-economic deprivation.¹⁵ People with disabilities are also far more likely to be victims of violence. Canadians with a disability, both women and men, were almost twice as likely to be victims of a violent crime than Canadians who do not have a disability. Women with disabilities and persons with mental health disabilities were particularly at risk of violence.¹⁶ Add to this poor access to appropriate housing, high rates of institutionalization¹⁷ and the poor access to disability supports, the general picture of being disabled in Canada is not one conducive to living a full and meaningful life.

The lack of appropriate supports also creates an increased reliance on family to provide supports. Feelings of burdensomeness observed in persons with disabilities has been associated with suicidal ideation or attempts.¹⁸ Data from Oregon shows that 48.9% indicate being a burden on family, friends/caregivers as a reason they have sought to end their lives.¹⁹ Canadian data shows a similar result with 34% of MAiD recipients citing perceived burden on friend, family or caregivers as a source of suffering.²⁰ As above, this is to a large degree a function of the presence or absence, and the adequacy, of, disability supports.

While the cases noted above seem to indicate the lack of acceptable care options is a major impetus in seeking MAiD, the general social position of many disabled persons in Canada can also lead to a life of struggling. The risk of opting for MAiD rather than continuing to struggle against the many barriers disabled persons face in trying to live a meaningful and fulfilling life is not one that can be lightly dismissed. This risk is arguably heighten in the context of austerity and concern with rising health and social care cost.

In their submission to the UN Human Right Committee, the major Canadian disability rights organizations note: Under Article 6, this Committee (UNHRC) has recognized the rights of persons with disabilities to “the effective enjoyment of the right to life on an equal basis with others.” States are required to provide “measures of protection” to guarantee this right, including “the provision of reasonable accommodation when necessary to ensure the right to life, such as ensuring access of persons with disabilities to essential facilities and services...” This Committee has interpreted Article 6 of the ICCPR with reference to Article 10 of the CRPD, which provides that “States Parties reaffirm that every human being has the inherent right to life and shall take

all necessary measures to ensure its effective enjoyment by persons with disabilities on an equal basis with others.” It is clear that the right to life includes obligations on states to ensure access to the social conditions necessary for meaningful enjoyment of the right.²¹ Canada is far from meeting its obligation under the Convention of the Rights of Persons with Disabilities, MAiD as currently defined in Canada, would seem to move us in the opposite direction.

NEGATIVE VALUATION OF DISABLED LIVES

The negative perception of the lives of persons with disabilities is well documented as Tuffrey-Wijne et al note: “Numerous reports in recent years have suggested that the lives of people with an intellectual disability are valued less across society, and that their short life expectancy results from inappropriate value-laden decision-making by healthcare professionals”.²² Gill in her review of evidence regarding physician attitudes towards disability and the impact on treatment decision found that health professionals tend to hold a negative view regarding the quality of lives of disabled persons and often more negative than that of the general public. She further notes that ‘Research has shown for some time that many health professionals believe life with extensive disabilities is not worth living’.²³ A recent study out of Harvard which surveyed 714 practicing US physicians found that 82.4 percent reported that people with significant disability have worse quality of life than nondisabled people. They note “these findings about physicians’ perceptions of this population raise questions about ensuring equitable care to people with disability. Potentially biased views among physicians could contribute to persistent health care disparities affecting people with disability”.²⁴

There is an extensive literature, along with copious anecdotal reports, regarding negative experiences with the health care sector by persons with disability.²⁵ These range from physical impediments to attitudinal barriers to reluctance/refusal to provide treatment, refusal of transplants, failure to undertake treatment that would normally be offered to a non-disabled person or undertaking non-medically necessary, highly invasive and high risk interventions.²⁶

If we look at other intersections of disability and health care, the picture does not improve. Current trends in pre-natal testing indicate a strong negative view towards having a child with a disability.²⁷ The potential to ‘eliminate Down’s Syndrome’ through pre-natal testing (PNT) and termination is now being discussed widely as a very positive development both with regards to the elimination itself and the potential cost savings which might be realized.²⁸ Disability scholars have argued that the practice of PNT and termination expresses strongly negative views towards persons with disabilities generally and promotes negative attitudes towards those persons currently living with a disability. Further, it has been argued that these views are the product of a false and biased view about disabled lives as ones of suffering and that suffering is inherent in the impairment itself rather than socially produced.²⁹

A further area which suggest this negative valuation of disabled persons in health care is the practice of neo-natal euthanasia. Legal in Belgium and the Netherlands, evidence suggests it is widely practiced elsewhere despite being illegal. A 2005 study³⁰ found that half the newborn

babies who died in Flanders over a recent year-long period (prior to legalization) were helped to die by their physician. Most were premature babies with severe congenital malformations or disabilities and what was described as a poor quality of life, or very premature babies with severe brain damage.

In 2002, the Groningen Protocol (GP) for neonatal euthanasia was developed in the Netherlands with the intent to regulate the practice of actively ending the life of newborns and to prevent uncontrolled and unjustified killing. Significant numbers of these cases involve neo-nates with non-life threatening, medically treatable conditions and disabilities, most commonly spina bifida.³¹ The American College of Pediatricians note that there is much room for parental, physician, personal, social, and economic bias. In their review of all 22 cases reported to the district attorneys' offices in the Netherlands from 1998-2005 Verhagen & Sauer³² found that all involved spina bifida. They report that the considerations used to decide on euthanizing included: expectation of extremely poor quality of life (suffering) in terms of functional disability, pain, discomfort, poor prognosis, and hopelessness; predicted lack of self-sufficiency; expected hospital dependency; and, long life expectancy. What is striking here is that none of these cases were terminal nor apparently experiencing significant physical pain. In all cases these were largely third party, subjective determinations of perceived future quality of life. It is not an unreasonable proposition that similar consideration would influence the practice of MAiD.

One might argue that while there are risk with regard to MAiD and disability, ethical considerations will mitigate any risk that this may pose for persons with disabilities. The reality is however that ethics may not only fail to protect, but actually support the use of MAiD with persons with disabilities. Certain streams in medical ethics are often explicitly hostile to the interest of persons with disabilities. This is most evident in, but not exclusive to, certain strains of Utilitarian ethics. Singer's views with regards to disabled persons, moral status and the ethics of euthanasia are perhaps best known.³³ He is far from alone however. One of the key concerns from the disability community is the equating of disability directly with suffering. John Harris writes with regards to prenatal testing and elimination of disabled fetuses that 'where we know that a particular individual will be born 'deformed' or 'disfigured' ...the powerful motive that we have to avoid bringing gratuitous suffering into the world will surely show us that to do so would be wrong'. He goes on to state that in the case of severe disability 'we should give them a humane death by legalizing euthanasia in such cases'.³⁴

One of the key features of all of these arguments is the assumption of 'suffering' as inherent to disability. As Tuffrey-Wijne et al note: 'the fact that the disability itself, rather than an acquired medical condition, can be accepted as a cause of suffering that justifies euthanasia is deeply worrying.'³⁵ Where this becomes most concerning is when it is operationalized through approaches like Quality Adjusted Life Years (QALYs) to determine what, if any, interventions offer the best cost benefit outcome.³⁶ Leading bioethicists³⁷ have endorsed the view that utilitarianism requires discrimination against the disabled in the allocation of health care resources based on the maximization of quality adjusted life years.³⁸ As Hilliard states, 'Consistent with the utilitarian

ethic, state sanctioned killing of those deemed to have "lost their dignity" is hailed as a "good."³⁹ Studies have shown that nondisabled persons tend to assign lower quality to disabled lives than disabled persons themselves.⁴⁰ The outcome then is that disabled persons will virtually always lose in the resource allocation calculus. In the context of MAiD, use of QALYs or similar methods raises some very serious concerns. As Barrie notes, 'problems (with QALY) relate closely to the debate over euthanasia and assisted suicide because negative QALY scores can be taken to mean that patients would be 'better off dead'.⁴¹

If the proposition that there is an inherent negative bias towards disability and disabled lives within health care and some ethical norms and systems, it is not difficult to imagine a scenario where disabled persons are counselled, or even encouraged to consider MAiD. This is particularly concerning with regards to newly disabled persons or those experiencing severe and prolonged mental health challenges. Studies have established that while persons who experience a traumatic injury resulting in disability will often and understandably go through periods of depression and hopelessness as they adjust to their new reality. However most do adjust to their new reality and report a satisfactory quality of life if they are provided with the mental health and disability supports required.⁴² Unfortunately studies have also reported limited access to mental health supports after traumatic injury.⁴³ All of this strongly suggests the 90 day wait period in the amended Federal law is far too short to avoid premature and needless suicide.

MAiD AND INTELLECTUAL AND DEVELOPMENTAL DISABILITY (IDD)

While it is often assumed people with IDD and ASD would not be eligible for MAiD due to the consent requirements, this is a clearly false assumption. Tuffrey-Wijne et al have shown significant numbers of people with IDD have accessed euthanasia in the Netherlands.⁴⁴ The current and proposed changes to Canadian MAiD laws significantly heighten the risk to persons with IDD which I will not describe in depth here but will highlight key areas of concern.

The question of consent is particularly concerning for a number of reasons. Tuffrey-Wijne highlight a number of concerns in the cases they reviewed in the Netherlands. In their analysis of the data they raise serious concerns about both the difficulties in assessing whether the patient had made a "voluntary and well-considered request" (one of the legal due care criteria), which as they note, is closely linked to an assessment of the patient's decision-making capacity, and the stringency of the assessments used to make the above determinations.⁴⁵ It should also be noted that many people with IDD are legally able to consent. Article 12 of the CRPD⁴⁶ in fact confirms the right of all disabled persons to make their own decision and to be provided with support as required. While this is an important clarification generally, in the current Canadian MAiD context it raises a number of concerns where the simple presence of IDD and declaration of intolerable suffering is all that is required to access MAiD. Many individuals with IDD have a tendency to respond in ways they feel others would want them to. In a context where family or support workers or health care professionals felt they may be better off accessing MAiD than say undergoing a non-life threatening medical intervention there is a risk that compliance will not

represent their true will and preference. While issues of subtle coercion or wanting to please are fairly straight forward, a potential further risk comes with the weakening of direct contemporaneous consent as in advance directives.

Once we move to a regime that does not require a direct contemporaneous consent we have raised the level of uncertainty as to whether this represents the person's true will at the time of administration. It is well document that many people approved for MAiD or similar AS procedures often change their minds. Without contemporaneous consent this change of will cannot be recognized. A further and more concerning issue is if we allow others to make the final decision, as would be the case with Advance Directives, have we opened the door to substitute or supportive decision makers to agree to MAiD on the persons behalf? Regrettably both the murder of people with IDD and murder-suicides by families who can no longer cope with the demands of caring without appropriate support, in despair, choose to collectively end their lives.⁴⁷ It is not inconceivable that families with decision making control or influence will choose MAiD as an alternative to struggling with insufficient support. The Corriveau case is another example where a mother of two children with significant disabilities forced to live in an institutions campaigned for the right to end their lives to wide spread public sympathy.⁴⁸ All of this suggests significant risks as MAiD laws becoming increasingly permissive.

CONCLUDING COMMENTS

While the expansion of MAiD has been motivated by a desire to end suffering and respect autonomy, in doing so we have created significant risk to persons with disability. The legal debate on MAiD has always been one of finding the balance between respecting individual's right to decide on how they end their lives and protecting the vulnerable. It is my opinion that balance has now shifted to a dangerous imbalance that creates extreme risks that people with disabilities will now die not out of a desire to end their lives but out of desperation or despair from a lack of supports which would allow them to live the best life possible with their disability. They will increasingly be victims of a world that views their lives as less valuable, as ones of inevitable suffering and not worth living. We have enough evidence now to show this is not a hypothetical concern. So the question is are we willing to sacrifice the lives of disabled citizens to ensure a broad right for the majority population to access MAiD when and how they choose? While I would like to offer suggestions on how we can safeguard the vulnerable within the current and evolving regime, current Canadian law has passed a point where safeguards can fully protect disabled persons. Some things that may help include: elimination of disability as a standalone eligibility criteria; extended timelines for those not at the end of life; more rigorous evaluation of consent and capacity for persons with IDD; strict prohibition on substitute consent; and, detailed psychosocial assessment and active remediation of unmet needs for disability supports all may lessen the risk.

It is in my view imperative that we step back and look seriously at the issues around the disabled and other vulnerable persons. It is no longer hyperbole that we are at risk of uncritically heading

to a place where the phrase ‘better dead than disabled’ becomes an underlying, if unspoken, driver of policy and practice. Thank you for giving me the opportunity to speak with you today.

¹ <http://www.vps-npv.ca/stopc7>

² UN Human Rights Office of the High Commissioner. 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>

³ Evidence of Gerard Quinn, United Nations Special Rapporteur on the Rights of Persons with Disabilities, United Nations Human Rights Council, Senate, Standing Committee on Legal and Constitutional Affairs, *Evidence*, 43-2 6 (1 February 2021), online: <https://sencanada.ca/en/Content/Sen/Committee/432/LCJC/10ev-55128-e>

⁴ Mandates of the Special Rapporteur on the rights of persons with disabilities; the Independent Expert on the enjoyment of human rights by older persons; and the Special Rapporteur on extreme poverty and human rights” (3 February 2021) UN Doc OL CAN 2/2021 [February 2021 Joint Communication to Canada]

⁵ See for a summary of cases: Submission of British Columbia Aboriginal Network on Disability Society (BCANDS), Council of Canadians with Disabilities, DisAbled Women’s Network Canada, Inclusion Canada, and Vulnerable Persons Standard to the Human Rights Committee. On the List of Issues Prior to Reporting for Canada to be adopted during the 132nd Session of the Human Rights Committee (28 June to 23 July 2021). May 21, 2021.

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⁷ Tu Thanh Ha. Montrealers file civil suit over assisted-dying laws. *Globe and Mail*, JUNE 14, 2017.

⁸ B.C. man with ALS chooses medically assisted death after years of struggling to fund 24-hour care
CBC News · Posted: Aug 13, 2019 · <https://www.cbc.ca/news/canada/british-columbia/als-bc-man-medically-assisted-death-1.5244731>

⁹ Testimony of Jonathan Marchand, Senate, Standing Committee on Legal and Constitutional Affairs, *Evidence*, 43-2 (1 February 2021), online: <https://sencanada.ca/en/Content/Sen/Committee/432/LCJC/10ev-55128-e>

¹⁰ Statistics Canada. Type of Collective Dwelling (16), Age (20) and Sex (3) for the Population in Collective Dwellings of Canada, Provinces and Territories, 2016 Census. <https://www12.statcan.gc.ca/census-recensement/2016/dp-pd/dt-td/Rp-eng.cfm?TABID=2&LANG=E&APATH=3&DETAIL=0&DIM=0&FL=A&FREE=0&GC=0&GK=0&GRP=1&PID=109537&PRID=10&PTYPE=109445&S=0&SHOWALL=0&SUB=0&Temporal=2016&THEME=116&VID=0&VNAMEE=&VNAMEF=>

¹¹ See for example: Stainton, Tim and Steve Boyce. 'I Have Got My Life Back': User's Experience Of Direct Payments.'. *Disability & Society*. 19.5 (August 2004): 443 - 454; Fleming P, McGilloway S, Herson M, Furlong M, O'Doherty S., Keogh F, Stainton T. (2019) Individualised funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review. *Campbell Systematic Reviews Oslo Vol. 15*, (Jan 25, 2019). DOI: 10.4073/csr.2019.3

¹² Wait times for direct funding for attendant care in Ontario is currently about a year, although wait times were historically even longer than this because of limited funding: Direct Funding Ontario, “Waiting List: How the waiting list works”, online: <https://www.dfontario.ca/application/waiting-list.html>

¹³ Morris, S. Fawcett, G. Brisebois, L. Hughes, J. Canadian Survey on Disability Reports: A demographic, employment and income profile of Canadians with disabilities aged 15 years and over, 2017. Statistic Canada. Release date: November 28, 2018. <https://www150.statcan.gc.ca/n1/pub/89-654-x/89-654-x2018002-eng.htm>

¹⁴ Morris et al.

¹⁵ See: Curtis, B., Curtis, C., & Fleet, R. W. (2013) Socio-economic factors and suicide: The importance of inequality. *New Zealand Sociology*, 28 (2), 77-92; Burrows, S., Auger, N., Roy, M., & Alix, C. (2005) Socio-economic inequalities in suicide attempts and suicide mortality in Québec, Canada, 1990–2005. *Public Health*, 124 (2), 78 – 85; World Health Organization (2000). Preventing Suicide: A resource for general Physicians. *Department of Mental Health*. Geneva: WHO.

¹⁶ Statistics Canada (2018) Violent victimization of women with disabilities, 2014.

¹⁷ Submission, BCANDs et al.

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⁴⁴ Tuffrey-Wijne et al 2018; 2019.

⁴⁵ Tuffrey-Wijne et al 2018.

⁴⁶ CRPD Article 12 - Equal recognition before the law includes:

1. States Parties reaffirm that persons with disabilities have the right to recognition everywhere as persons before the law.
2. States Parties shall recognize that persons with disabilities enjoy legal capacity on an equal basis with others in all aspects of life.
3. States Parties shall take appropriate measures to provide access by persons with disabilities to the support they may require in exercising their legal capacity.

⁴⁷ Perry, D. (2017) On media coverage of the murder of people with disabilities by their caregivers. *Rudderman Foundation*; Coorg R, Tournay A. Filicide-suicide involving children with disabilities. *J Child Neurol*. 2013 Jun;28(6):745-51. doi: 10.1177/0883073812451777. Epub 2012 Jul 22. PMID: 22826515.

⁴⁸ Dr. Phil: Promoting Killing People with Cognitive Disabilities – And a Close Encounter in 2002
<https://notdeadyet.org/2012/04/dr-phil-promoting-killing-people-with.html>
