Position of the Quebec Intellectual Disability Society on Bill 11

An Act to amend the Act respecting end-of-life care and other legislative provisions

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About Us

The Quebec Intellectual Disability Society brings together, informs and equips all those who wish to make Quebec a more inclusive society, where everyone can find their place and flourish. More than 90 organizations and associations, over 150 employers and thousands of families across the province are already part of the movement.

Basing its actions on the fundamental principles set forth in the Universal Declaration of Human Rights and in the Quebec and Canadian Charters, the Quebec Intellectual Disability Society strives to

- promote the interests and defend the rights of people with intellectual disabilities and their families, either by acting proactively, notably by lobbying on various policy issues affecting people with intellectual disabilities and their families, or by intervening in situations of crisis, discrimination or exploitation of these people.

- inform and sensitize members, partners, professionals and stakeholders, as well as decision-makers and the general public, on issues and new developments in the field of intellectual disabilities. It does this through publications and media relations as well as by organizing events such as theme days, conferences and awareness campaigns.

- act as a spokesperson for the individuals, families, associations and organizations it represents with the various political and public authorities or social actors, particularly with regard to the various bills and regulations in the fields of education, work, health, social services, income security or any programme that directly or indirectly affects the social inclusion of the people whose cause it supports.

- encourage and support any initiative that prioritizes services and support for natural families or facilitates the autonomy of people with intellectual disabilities, and therefore promotes their full inclusion in their respective communities.

- Promote the sharing of expertise and the creation of solidarity networks.

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Introduction

Historically, people with intellectual disabilities have often had their rights to health and life denied when they suffer from serious or degenerative illnesses. Thus, although life expectancy for people with intellectual disabilities has increased rapidly in recent decades, they still experience a higher mortality rate for preventable deaths than the rest of the population (Trollor et al. 2017), due to a lack of adequate care and management in the health and social services network. These factors, coupled with a higher risk of developing serious or degenerative diseases at a younger age (Strydom et al. 2007; 2009), make it necessary to protect vulnerable people in the arrangements for access to medical assistance in dying (MAiD).

Since medical assistance in dying is practised in Quebec and there is a discussion about the possibility of extending it to cases other than those currently provided for in the Act, it is important to ensure that vulnerable people are adequately protected.

In recent years, the Society has been active on the issue of medical assistance in dying, testifying before the Quebec National Assembly as well as the House of Commons and the Senate. For the Society, it is important to adequately protect the most vulnerable people in our society, while respecting the wishes of those who are capable of making informed decisions regarding medical assistance in dying. This balance is difficult to achieve, but it is clear that the protection of the vulnerable should be a priority for the legislative framework of medical assistance in dying.

This brief presents the Society's position on Bill 11, which is currently being studied by the Quebec National Assembly.

I. Preliminary remarks

A fundamental paradigm shift

Bill 11 proposes a major paradigm shift in the regulation of medical assistance in dying (MAiD). By proposing to open MAiD to people who are not at the end of their lives and to people with disabilities, Bill 11 represents a significant change in the way MAiD is conceived and how it can be used. This paradigm shift is major and could have unforeseen effects on the vulnerable people that the Quebec Intellectual Disability Society (the Society) represents. It is fundamental that people with disabilities and the organizations that represent them be heard and listened to.

From the outset, it is crucial to specify that the Society is not opposed to medical assistance in dying for people at the end of their lives who are capable of giving consent. Rather, we ask that adequate safeguards be put in place to ensure that no abuse happens, particularly with regard to vulnerable persons. It is also important to note that the Society recognizes that healthcare professionals are motivated by a form of benevolence and that the reservations mentioned in this opinion are not intended to discredit these essential workers.

For the Society, MAiD is not a "treatment" like any other. It is an irreversible medical act that seeks to bring an unnatural death to the person receiving it. A distinction must be made between the act of inducing death and the act of allowing natural death to occur while providing palliative care. The semantic confusion between 'treatment' and 'medical act' has very real impacts on how the MAiD is presented to the public and how the public understands and supports the practice. While this medical act may be perfectly acceptable and desired by individuals in specific contexts, it is important not to commodify the practice.

In this sense, we believe that the legislator must be cautious and consider the systemic forces that could threaten people with disabilities and specifically people with intellectual disabilities.

Ableism and medical assistance in dying

In order to understand where society's reservations about the bill come from, it is important to remember that people with disabilities have historically been the object of attitudes and beliefs that devalue their abilities, their social value and sometimes even their lives. This is commonly referred to as ableism (Office québécois de la langue française 2023; Campbell 2009).

Although things have progressed, ableism is still deeply rooted in the way things are done, in biomedical research and in society in general (Janz 2019; Tarvainen 2019). Ableism is mostly not a conscious attitude of people, but rather a set of values and attitudes internalized from an early age. In short, everyone without exception is likely to display ableism. These attitudes have an important impact on how people with disabilities are perceived in society and therefore included. This is particularly true for people with intellectual disabilities, who are often perceived as less valuable because of the importance given to intelligence in modern societies (Schalock 2011).

Ableism also has impacts on the way people with disabilities are treated in health systems around the world. Studies have shown that people with disabilities have higher than average mortality rates for preventable causes of death due to lack of access to adequate care (Trollor et al. 2017).

2017). Erroneous or unfounded beliefs about people with disabilities also have a profound impact on how health professionals view the quality of life or level of suffering of people with disabilities (Crocker, Smith, and Skevington 2015). Several studies show that health professionals tend to systematically view the quality of life of people with disabilities as worse than the individuals themselves (Addington-Hall and Kalra 2001).

In sum, ableism is still a strong force in society and deserves to be taken into account when considering a bill such as Bill 11. Thinking about unconscious biases towards certain populations is useful in thinking about the unintended effects of such a measure and its potentially problematic consequences.

II. Disability as a criterion for access to MAiD

It should be noted here that intellectual disability, or disability in general, should never be the only criterion for access to the MAiD. Although it is appropriate to put in place specific measures for people with disabilities in order to achieve substantive equality (Robert Masson and Martha Butler 2021), access to MAiD is not one of these cases. We appreciate the nuance in the bill, as Article 14 refers to "severe neuromotor disabilities"[1], but it remains worrying that disability appears in the law as a possible criterion for access to the MAiD.

Furthermore, the notion of "foreseeable evolution of the disability" (Art. 17) is also a difficult issue to resolve in practice. Although biomedical research is capable of predicting the course of a disease, these predictions remain the expression of calculated probabilities. In this sense, basing access to MAiD for a specific person on probabilities drawn from large samples is contrary to the individual assessment of a person's condition. Many people beat the odds.

With the necessary support and appropriate accommodations, persons with intellectual and other disabilities can live full and rich lives. If individuals find themselves living with intolerable suffering in relation to their disability, it is usually because society does not include them and because they lack services. There have been numerous media reports of persons with disabilities deciding to apply for the MAiD because of the extreme poverty in which they find themselves (Cecco 2022; Padraig Moran 2022; Cynthia Mulligan and Meredith Bond 2022). These heartbreaking situations point to an uncomfortable reality and it does not seem that the extension of MAiD is an adequate response.

Using disability as a criterion for access to the MAiD also raises questions about the negative signal sent to the public about the value of the lives of persons with disabilities. If dying is preferable to living with a disability, how can people with disabilities enjoy a full and rich life? Are we saying that they ought to have recourse to MAiD? Yet quality of life is a subjective assessment that is contested in bioethics (Langley 2020), not least because medical staff routinely assess the quality of life of people with disabilities or other vulnerable people in a negative way (Moons, Budts, and De Geest 2006), or are unable to objectively assess their quality of life (Townsend-White, Pham, and Vassos 2012).

Furthermore, although health professionals must ensure that 'the request is made freely, among other things by checking that it is not the result of external pressure', this requirement may be difficult to achieve in many cases related to persons with disabilities. The internalized devaluation of many persons with disabilities and the perception of being a burden could lead to recourse to MAiD, due to the lack of services, in order to "relieve" caregivers (Santé Canada 2020). It is

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[1] If adopted, this concept will need to be clarified as much as possible in order to provide a clear definition. The experience of the first version of the triage protocol for access to intensive care in the context of the COVID-19 pandemic in Quebec has shown that vague concepts can lead to major uncertainties and numerous problems of social acceptability.

important to assess and understand the reasons why people with disabilities or who are not at the end of life request MAiD.

In this sense, the limited consideration given to the social determinants of health (including poverty) is notable. As more and more newspaper articles describe the situation of persons with disabilities who have decided to apply for MAiD because of their severe poverty (Brennan Leffler and Marianne Dimain 2022), it is worrying that the assessment of applications is almost solely focused on medical aspects. It is crucial that legislators adapt their assessment and data collection processes to take into account the social determinants of health, including poverty, as these factors may explain many MAiD applications from vulnerable people (Santé Canada 2020).

In the specific case of people with intellectual disabilities, as well as in cases of advance requests, it is questionable whether all such people will be able to understand the nature of the diagnosis and the "predicted course of the disease" when applying for MAiD. There are significant risks of undue pressure being applied, even to those otherwise able to consent. Difficulties in abstract thinking and in projecting oneself into the future, as well as the desire to conform to the expectations of family and friends, are important characteristics of intellectual disability. It is therefore questionable whether these people will be able to consent on their own without being influenced by third parties. Furthermore, while people with intellectual disabilities may experience distress in relation to the death of someone close to them (Chow et al. 2017), it is generally more difficult for them to understand the permanent and irreversible nature of their own death (Dusart 2008). Because of the tension between 'self-determination', respect for the autonomy of individuals, and the protection of people in vulnerable situations, the legislator should prioritize the protection of the latter, as MAiD is by definition irreversible.

Thus, for the Society, the sole capacity to consent should not be sufficient for a person in a situation of vulnerability to apply for MAiD. Additional safeguards should be put in place and the social determinants of health have to be taken into account and assessed in detail.

While it is clear that the intention of the legislator is not to devalue the lives of people with disabilities, access to MAiD on the basis of disability does raise fundamental questions about the way people with disabilities are presented in the collective imagination. The good intentions and empathy that motivate legislators to include forms of disability in the bill are unfortunately likely to do more damage than they will do good.

III. Access to MAiD through advanced directives

While the Society understands the motivations behind the legislator's desire to make it legally possible to formulate advance consent to MAiD, and acknowledges that there is some form of consensus in the population, it has significant reservations about the proposed practice. These reservations are linked to the way in which the practice would be regulated, but also relate to the validity of advance consent as such.

Formulation of the advance request

The Bill provides that advance requests should be made in the context of a person "suffering from a serious and incurable illness leading to incapacity to consent to care" (art 18, creating art 29.1). We are reassured by the fact that only the person requesting MAiD can make an advance request (art. 18, creating 29.2). We were indeed concerned about the possibility for third parties to apply for MAiD on behalf of a person who is incapacitated or not able to understand the issues related to the procedure (Société québécoise de la déficience intellectuelle 2022).

Assessment of the condition of persons with disabilities

For the Society, the possibility of "objectively" assessing a person's suffering is wishful thinking (art 18, creating 29.1). Indeed, the literature is clear on the fact that health professionals tend to devalue the quality of life of people with disabilities or neurocognitive disorders (Katsuno 2005; Conde-Sala et al. 2009). The same applies to the tools that can be used to analyze a person's situation, which were created by researchers with often unconscious and implicit cognitive biases. These problems were evident during the pandemic, particularly in the triage protocol for access to intensive care, which was deemed discriminatory. The protocol referred to measurement tools that could cause disproportionate harm to people with disabilities, without any real basis (Société québécoise de la déficience intellectuelle 2020).

In the absence of a satisfactory alternative, it is disturbing to think that the analysis of eligibility to receive MAiD will be carried out by human beings who may have unconscious biases towards people with disabilities or neurocognitive disorders, no matter how benevolent they may be or how much they may wish to do good.

Advance directives: not real consent

With regard to the legislator's desire to potentially allow the use of advance directives for access to MAiD, we wish to bring the question of the validity of consent back to the centre of the debate. Indeed, asking a third party to consent in a substituted manner to a procedure that leads to death is different from producing advance directives to refuse certain procedures that may lead to natural death.

In the case of advance directives in connection with MAiD, substituted consent is used to carry out a procedure leading to the person's death. The incapacitated person therefore does not consent at the time of the procedure and there is no clear way of knowing whether or not the person still maintains consent. In the case of directives to withhold care, the person chooses to stop care and provides direct consent for natural death to occur. In this sense, opening the door to substituted consent, even for persons who had previously consented, seems dangerous and does not respect the spirit of the Carter decision, which placed the issue of consent at the heart of access to the MAiD.

Notwithstanding these reservations, it is important to consider how substituted consent would work if the Bill is passed. Under the Bill, the assessment of the appropriateness of proceeding with the administration of MAiD is entrusted to professionals in the health care system (art 18, creating 29.13). For the Society, this is the lesser of two evils. Indeed, it is appropriate that trusted third parties should not be able to decide whether to administer MAiD for their relative, but efforts should be made to protect professionals in cases where trusted third parties might insist or attempt to exert pressure on administering the procedure. These discussions can be very emotional, and as with obstinate care, it is likely that some people will take extreme positions in relation to MAiD.

This is all the more important as the refusal of persons to receive MAiD is only mentioned in Article 18 creating 29.19 under the wording: "any refusal to receive medical aid in dying manifested by the person must be respected and may not be overridden in any way." However, this provision is nuanced by the following paragraph: "For the purposes of the third paragraph, a clinical manifestation arising from the person's medical situation does not constitute a refusal to receive medical assistance in dying". This provision raises very serious questions. How will health professionals be certain that such a manifestation is not a moment of lucidity beyond all reasonable doubt? How to ensure that the implicit beliefs and biases of health care staff will not colour their assessment of the situation? This is not insignificant since the assessment of the condition of unfit persons would be the responsibility of health professionals once the Act is passed.

It is also questionable to presuppose that prior consent is equivalent to the level of consent of a contemporary application for MAiD, even though the law provides for an assessment of "the manifestation of his or her consent to medical assistance in dying" (art 18 creating art 29.3). It is very difficult to assess the consent of persons who have become incapacitated, particularly in cases where the condition may lead to changing states from day to day or even hour to hour.

IV. Alternatives to MAiD are needed

We believe that it is essential to provide persons with disabilities with adequate alternatives. This is a position that has been put forward by the Canadian Human Rights Commission (Commission canadienne des droits de la personne 2022) and a number of groups representing persons with disabilities in Quebec and Canada. Universal and quality public services, in sufficient quantity, must be given to people who need them. This is an obligation that Canada has towards persons with disabilities under the Convention on the Rights of Persons with Disabilities (Organisation des Nations Unies 2006).

Thus, satisfactory alternatives are needed to provide a life of dignity for people with disabilities and for Canadians in general. As others have mentioned, it is time to ensure a right to live in dignity for people with disabilities rather than mobilizing considerable resources to ensure that they can end their lives.

Income support and home services should be provided to support the dignity of persons with disabilities and guarantee them an adequate quality of life. People with disabilities want to live and be included in society. It is the government's duty to contribute more meaningfully to this collective responsibility.

V. Other provisions

A few other provisions of the bill deserve to be highlighted or improved.

Mental health

We are pleased with the exclusion of mental health (art.15) in the bill, but remain extremely concerned. Persons with intellectual disabilities often live with mental health problems because of the forms of exclusion they experience.

Access to MAiD on the basis of mental health would be a direct incentive to suicide for people who are already living in very difficult situations and would sanction the fact that the problems of under-funding of public services and the systemic factors that contribute to more difficult mental health situations are secondary. This is a particularly worrying avenue.

Accountability

Accountability should be centralized at the Ministry of Health and Social Services, not divided between the Collège des médecins du Québec and the Ordre des infirmières et infirmiers du Québec (art 27).

The Commission on End-of-Life Care should also be given a specific mandate to monitor the use of MAiD by people with disabilities and collect more data related to the social determinants of health in order to better understand the dynamics at work. Provincial disability organizations should be involved in the work of the Commission.

Conclusion

In conclusion, we believe that MAiD should be a measure of last resort for people who are capable of giving free and informed consent and who, at the end of their lives, are living with intolerable suffering. We also distinguish between the issues of advance care directives and advance directives in relation to MAiD. The former allow for natural death, while the latter entail the use of an active procedure that ends life.

Furthermore, in our view, substituted consent should not be permitted for incompetent persons, since they cannot provide free and informed consent. The Carter decision put the issue of consent at the heart of access to MAiD. It is important to respect this fundamental principle of justice and health ethics.

Finally, in the event that people with intellectual disabilities at the end of their lives apply on their own, without any undue pressure, then we believe that they should be assessed like all other people, as long as their access to MAiD is not on the basis of disability. However, it is important to have more robust safeguards in place to prevent ableism and the devaluation of the lives of people with disabilities.

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