



**QUEBEC INTELLECTUAL  
DISABILITY SOCIETY**

Presentation by the Quebec Intellectual Disability Society  
to the Special Joint Committee on Medical Assistance in  
Dying

Parliament of Canada

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# About the Quebec Intellectual Disability Society

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 thrive. More than 90 organizations and associations, over 150 employers and thousands of families across the province are already part of the movement.

Guided by the fundamental principles set forth in the Universal Declaration of Human Rights and the Quebec and Canadian Charters, the Quebec Intellectual Disability Society works to

- Promote the interests and defend the rights of people with an intellectual disability and their families, either by acting proactively, notably by making demands in the context of the diverse political policies affecting people and their families, or by intervening in situations of crisis, discrimination or exploitation of these people.
- inform and sensitize members, partners, professionals and stakeholders in the field, as well as decision-makers and the general public, on issues and new developments in the field of intellectual disabilities. It does so through publications and media outreach as well as by organizing events such as thematic workshops, conferences and awareness campaigns.
- Act as a spokesperson for the individuals, families, associations and organizations it represents before the various political and public authorities or social actors, particularly with regard to the various legislative bills and regulations pertaining to education, work, health, social services, income security or any program that closely or remotely affects the social inclusion of the people whose cause it supports.
- encourage and support any initiative that promotes services and support for families or that facilitates the autonomy of persons with intellectual disabilities, and, consequently, that promotes their full inclusion in their respective communities.
- To promote the sharing of expertise and the creation of solidarity networks.

# Protecting People with Intellectual Disabilities from Substituted Decision-Making and Ableism in Medical Assistance in Dying: An Imperative for Legislators

Ladies and gentlemen, members of the Special Joint Committee on Medical Assistance in Dying (MAiD), we would first like to thank you for the opportunity you have given the Quebec Intellectual Disability Society today.

## Not an opposition to MAiD in general, but a need for guidance

We wish to make it clear that our organisation is not opposed to medical assistance in dying for people nearing the end of their lives<sup>1</sup>. Rather, we ask that adequate safeguards be put in place to ensure that no abuses occur. We believe that legislators must be cautious and consider the systemic forces that could threaten people with disabilities and specifically people with intellectual disabilities.

## Intellectual disability should never be a criterion for access to MAiD

It should be noted here that intellectual disability, or disability in general, should never be a criterion for access to MAiD. With the necessary support and appropriate accommodations, people with intellectual disabilities can live fulfilling and rich lives. If people find themselves living with intolerable suffering related to their intellectual disability, it is because society does not include them, and they lack services.

## Substituted consent for incapacitated persons in MAiD: danger!

The Society is also very concerned about the possibility of authorizing substituted consent for incapacitated persons at all stages of MAiD applications. This possibility had been

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<sup>1</sup> Our organisation does not have a position on the extension of MAiD to people living with mental health conditions or to mature minors.

raised by the Quebec National Assembly and, even if such a question is not under consideration today, it is important to discuss it.

On the one hand, the use of MAiD should always be tied to the validation of a free and informed consent from the person who will receive it; on the other hand, it may be difficult to assess this consent for incapacitated persons, especially those with a more severe intellectual disability. These persons may experience distress in relation to the death of someone close to them (Chow et al., 2017), but it is generally more difficult for them to understand the permanent and irreversible nature of their own death (Anne Dusart, 2008).

We therefore call on the legislator not to allow substituted consent for those who lack capacity to consent.

### Advance directives: not real consent

Regarding the legislator's desire to potentially allow the use of advanced directives for access to MAiD, we would like to refocus the debate on the issue of the validity of consent in these situations.

Asking a third party to consent to a procedure that leads to death through a substituted decision-making process is different from making advance requests to refuse certain procedures that may lead to natural death<sup>2</sup>.

In this light, opening the door to substituted consent, even for people who had previously consented, seems to us to be potentially dangerous and to fail to respect the spirit of the Carter decision which put the issue of consent at the heart of access to MAiD.

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<sup>2</sup> In the case of advanced directives in relation to MAiD, substituted consent is used to carry out a procedure leading to the person's death. Therefore, the person does not consent at the time of the procedure and there is no way of knowing whether or not the person still maintains consent.

In the case of refusal of care directives, the person chooses to discontinue care and provides direct consent for natural death to occur.

## Alternatives to MAiD are needed

In our view, it is important to provide satisfactory alternatives for people with disabilities. This position has been advanced by the Canadian Human Rights Commission (Canadian Human Rights Commission, 2022). Universal and high-quality public services, in sufficient quantity, must be provided to people who need them. Indeed, this is an obligation that Canada has towards people with disabilities under the Convention on the Rights of Persons with Disabilities (United Nations, 2006).

Thus, satisfactory alternatives are needed to provide a dignified life for people with disabilities and for the Canadian population in general.

## Closing Remarks

As mentioned previously, 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 life, are living in unbearable suffering. We also distinguish between the issues of advanced care directives and advanced directives in relation to MAiD. The former allows for natural death, while the latter entails the use of an active procedure that ends life without clear and validated consent.

Furthermore, we believe that substituted consent should never be allowed for incapacitated persons, as 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 health justice and ethics.

Finally, in the event that people with intellectual disabilities at the end of their lives make an application 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 granted on the basis of disability. However, it is important to have stronger safeguards in place to prevent ableism and the devaluation of the lives of people with disabilities.

## Bibliography

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