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

We wish to make it clear that our organization is not opposed to medical assistance in dying for people nearing the end of their lives.[1] 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.

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.

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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[1] It is important to note here that our organization does not have a position regarding the expansion of MAID for people with mental health disorders or for 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. If these persons experience distress in relation to the death of someone close to them, it is generally more difficult for them to understand the permanent and irreversible nature of their own death. We therefore call on the legislator not to allow substituted consent for those who lack capacity to consent.

Regarding the legislator's desire to potentially allow the use of advance 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.[2] 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.

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. Universal and high-quality public services, in sufficient quantity, must be provided to people who need them.

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[2] In the case of advance directives linked to MAID, substituted consent is used to carry out a procedure leading to the death of the person. The person therefore does not consent at the time of the procedure and there is no way of knowing whether or not the person still maintains their consent. In the case of directives to refuse care, the person chooses the decision themselves. care and provides direct consent for natural death to occur.

Indeed, this is an obligation that Canada has towards people with disabilities under the Convention on the Rights of Persons with Disabilities. Thus, satisfactory alternatives are needed to provide a dignified life for people with disabilities and for the Canadian population in general.

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 advance care directives and advance 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, if 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, so 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.

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