

October 27, 2016

The Honourable Jody Wilson-Raybould, P.C., M.P.
Minister of Justice and Attorney General of Canada
House of Commons Ottawa, Ontario, K1A 0A6

& The Honourable Jane Philpott, P.C. M.P.
Minister of Health
House of Commons Ottawa, Ontario, K1A 0A6

Dear Minister Wilson-Raybould and Minister Philpott,

Re: Terms of Reference for Independent Reviews of Issues Relating to Requests for Medical Assistance in Dying

We are writing with recommendations for the terms of reference for the independent studies the government is committed to commissioning under section 9.1 of the amendments to the *Criminal Code*. These studies relate to accessing medical assistance in dying on the basis of requests through advance directives, solely on the basis of mental health conditions and in response to requests from mature minors. As Advisors and Partner organizations in the Vulnerable Persons Standard (VPS) community we have particular interest in how these studies are formulated and conducted. As you know, our community is working to ensure that the design and implementation of a system in Canada for medical assistance in dying does not jeopardize vulnerable persons who may be subject to inducement, coercion and abuse.

The issues to be considered in these studies are deeply complex, admitting of many ethical, social and legal dimensions. As such, they are profoundly troubling to many Canadians. This is in part due to the fact that frameworks for analysis have not been fully elaborated, empirical research on these topics is relatively scarce, relevant research questions are still in formulation and structured forums for public consultation and dialogue on these matters are not yet in place. The government's studies, if carefully framed, can assist Canadians to navigate this difficult terrain. To that end, our recommendations are as follows:

1. The purpose of the studies should be to foster reflection and deliberation among Canadians

The preambular commitment to “explore other situations — each having unique implications — in which a person may seek access to medical assistance in dying” must be the overall aim guiding the terms of reference and the tenor of these studies, the operative word being “explore”. What should we expect of these studies? We urge that the intended outcome be to

foster reflection and deliberation among Canadians and create fertile ground for reaching better understanding of the issues.

The matters of advance directives, access on the basis of mental health conditions and for mature minors were extremely polarizing in Canadian media, in public and private discourse and in Parliament in the period leading up to the legislation being adopted. They continue to be so. Given this fact, and that the system is just beginning to be designed and implemented, we think it critically important that the terms of reference be exploratory in nature. To the extent that these studies set a thoughtful and reflective tone, they will be most likely to encourage a well-informed and productive deliberation, rather than a highly polarized and politicized process of advocacy for a particular outcome.

2. The studies should be mandated to report ‘findings’ rather than ‘recommendations’

To achieve this overriding aim, we recommend that the primary objectives for the studies be to:

- a. synthesize key findings from published research in medicine, psychology and social science; theory, opinion and commentaries from experts in relevant fields nationally and internationally, and inputs from the Canadian public and civil society;
- b. summarize the range of ethical, social, legal and human rights perspectives to be considered;
- c. reflect upon the perspectives of persons most likely to be directly affected by law reform in these areas, and their representative organizations;
- d. provide leadership for a well-informed, reflective and respectful public dialogue about the implications of potential law reform in these areas; and
- e. identify gaps in our current knowledge and opportunities for further research and reflection.

Without this clarity about the objectives, we are concerned that there will be pressure to move precipitously toward specific recommendations for law reform related to access through advance directives, mental health conditions, and in response to requests from mature minors. We believe it is not yet time for this stage of work, and that the focus should be on outlining the knowledge base, and examining and reflecting on the issues. Focusing on findings rather than recommendations will allow for a fulsome exploration that appropriately balances formal research, expert commentary and experiential perspectives.

3. Three studies should be conducted

In designing terms of reference for the studies, we believe it critically important to balance three main concerns:

- Need for a full elaboration of guiding values, ethical perspectives, societal, institutional and legal considerations;
- Need for a shared understanding of what ‘vulnerability’ means in the context of a system for medical assistance in dying, and the risks that must be addressed; and

- Need for a substantive investigation of each of the three areas – advance directives, mental illness as sole condition and mature minors.

Keeping these concerns in mind, we recommend that three studies be conducted:

a. Study on a guiding framework of principles and key concepts

This study would develop a framework that addresses relevant social context, key concepts like the nature of suffering, core values and beliefs, and ethical and legal principles as these relate to medical assistance in dying for the three areas under consideration. The study would examine perspectives to be considered in achieving the preambular commitment to “the most appropriate balance between the autonomy of persons who seek medical assistance in dying, on one hand, and the interests of vulnerable persons in need of protection and those of society, on the other...” A systematic examination is needed of the histories, values, beliefs and ethical and legal principles that must be understood in order to achieve this balance when it comes to considering new grounds of access. This study should draw from multiple lenses to consider the implications, for example, of gender and gender identity, race and ethnicity, faith, disability, class and other social locations. In addition, this study should explicitly consider:

- concepts of suffering, its expression, the range of appropriate ethical and health system responses, and the nature of state obligations;
- the social and cultural dimensions of medical assistance in dying within indigenous cultures;
- different framings of mental health and mental illness in both academic and advocacy/consumer communities; and
- the extent to which mental illness can be distinguished, if at all, from other types of mental disability, such as intellectual and cognitive disability or autism spectrum disorder, in considering equal grounds for access.

b. Study on vulnerability in the context of medical assistance in dying for mature minors, for persons for whom mental illness is the sole underlying medical condition and for persons whose request is made by advance directive.

This study should examine:

- the concept of vulnerability and in particular its relationship to the social determinants of health;
- evidence on how coercion, inducement and abuse operate;
- evidence of how vulnerability figures, both procedurally and substantively, in other permissive jurisdictions;
- social and psychological accounts of how vulnerability is produced in this context;
- systemic risk factors that could increase vulnerability particularly where systems are fragmented and guidelines vary by jurisdiction and issuing authority, or where there is lack of clarity about regulatory authority; and

- particular risks that could come with introducing access through advance directives, solely on the basis of mental health conditions and for mature minors.

Other specific areas to be addressed in this study should include the need for and possible approaches to vulnerability assessment, and the question of how suicide prevention policy and practice would articulate with medical aid in dying as it affects minors, persons with mental health conditions and persons authoring advanced directives.

c. *Study on evidence and medical and legal perspectives related to medical assistance in dying for mature minors, for persons for whom mental illness is the sole underlying medical condition and for persons whose request has been made by advance directive.*

We recommend this study be informed by and conducted in a way to be coherent with the first two studies. This study should have a particular mandate to consider each of these areas of access in relation to the preambular commitment to secure “the most appropriate balance between the autonomy of persons who seek medical assistance in dying, on one hand, and the interests of vulnerable persons in need of protection and those of society, on the other...” The terms of reference should require dialogue with and input from the two studies outlined above. The study should consider research and evidence related to each of the three areas of access and be mandated in such a way as to explicitly consider each of the three perspectives identified in the preamble of the new law, namely:

- individual autonomy;
- vulnerable persons and the production of vulnerability; and
- social cohesion and its antecedents.

4. The study process should be carefully constructed, with deliberate articulations between each distinct study.

Our specific recommendations are as follows:

- Each study should be co-chaired by highly regarded and respected Canadians, each co-chair bringing distinct perspectives – bio-medical, ethics, law, and/or social science – a mix of all of these perspectives should be embodied by the six co-Chairs appointed.
- Each co-chair pair should designate one person with lead responsibility for public education and communication at all phases of the study, permitting a clarity of intellectual leadership so that the work of the study team is framed from start to end in ways that are meaningful, accessible, constructive and transparent.
- An Advisory Group for each study should bring relevant experts and interests to the table – maximum of eight advisors per study, and a mix of experts and social

identities representing youth, older persons, persons with disabilities, indigenous and diverse ethno-racial-cultural perspectives.

- A joint secretariat of officials from Departments of Justice, Health, and Employment and Social Development Canada should be mandated and resourced to provide research support and technical expertise.
- Appropriate communications expertise and resources should be provided to maximize the capacity for designated study co-chairs to fulfil their role in shaping a constructive national dialogue.
- An online consultation with Canadians should be provided for, with opportunity for input to each of the studies through online surveys and submission of briefs.

We believe that terms of reference structured along the lines outlined above would enable needed elaboration of issues, evidence and perspectives. We urge the studies be designed in a manner to maximize the prospects and potential for reasoned dialogue among Canadians on these difficult issues. Ultimately, the studies must provide the much greater clarity and understanding that Canadians are calling for on these matters, and on which any recommendations for reform can later be fruitfully formulated and considered.

Sincerely,

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Alliance for Equality of Blind Canadians
ARCH Disability Law Centre
Autistic Self Advocacy Network Canada
Brockville & District Association for Community Involvement
Canadian Association for Community Living
Canadian Down Syndrome Society
Canadian Society of Palliative Care Physicians
Catholic Health Alliance of Canada
Centre for Inclusion and Citizenship
Citizens with Disabilities – Ontario
Communication Disabilities Access Canada
Community Living Selkirk
Council of Canadians with Disabilities
Disabled Women's Network of Canada
Durham Association for Family Respite Services
Inclusion Alberta
Inclusion BC
Legacies Inc.
National Network for Mental Health
PEI Council of People with Disabilities
St. Joseph's Health Care London