

# **Protecting Choice & Safeguarding Inclusion**

## ***A Proposal to Regulate Physician-Assisted Suicide and Voluntary Euthanasia in Canada***

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**The Canadian Association for Community Living**

**With People First of Canada**

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**Canadian Association  
for Community Living**  
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l'intégration communautaire

Diversity includes. On se ressemble.

The Canadian Association for Community Living (CACL) is a national, family-based association and federation of over 40,000 members, 300 local and 13 provincial/territorial Associations for Community Living. CACL is dedicated to attaining full participation in community life, ending exclusion and discrimination on the basis of intellectual disability, promoting respect for diversity and advancing human rights to ensure equality for all Canadians.

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## Plain Language Summary

The Supreme Court of Canada has decided that physician-assisted suicide and voluntary euthanasia are no longer against the law.

- “Physician-assisted suicide” is when a person kills him/herself with the help of a doctor.
- “Voluntary Euthanasia” is when a person asks a doctor to kill him or her.
- In both cases, a doctor gives drugs that will kill the person.

The Court has said that adults should be able to access a system to do this when:

- They have a medical condition that causes them to suffer all the time.
- They can make the decision all by themselves.
- They are not vulnerable to being pushed into dying by other people or their situation.
  - Being vulnerable in this way means: You are choosing to die because another person is pushing you to make this choice. Or, you are choosing to die because of other reasons – like being all alone, poor, unable to support yourself, without people who care about you, or who can assist you to live, or because you are being abused by someone.

To make sure people have a real choice, and also that vulnerable people are not pushed into dying, we have made a proposal called: *Protecting Choice & Safeguarding Inclusion*. The goal is:

**To make sure people can choose physician-assisted suicide or voluntary euthanasia, but only as a real choice. This means they must not be pushed into dying by others, or because of poverty, lack of support, or abuse. Other options must always be provided. The system must safeguard inclusion of vulnerable persons in society.**

Our plan is based on the UN *Convention on the Rights of Persons with Disabilities* and includes:

### 1. Core Values

- Autonomy – real choice
- Dignity – self-respect and self-worth
- Inclusion – having options and support to live a good life

### 2. Principles and Guidelines

- We have created guides for governments and doctors to create a system based on these values

### 3. Vulnerability Assessment and Informed Consent

- People who choose to die must first have someone else find out if they are being pushed to die or are vulnerable.

- If they are vulnerable, steps must be taken to put in place the supports a person needs to continue living in the community.
- A person must be able to make, understand and communicate the choice. They must be able to do this by themselves. A person's support network cannot make or communicate this choice for a person.

#### 4. Advance Independent Review and Approval

- A request to die should be approved by an independent panel, which will either approve or deny the request. When the panel believes the person is too vulnerable or not able to make this decision on his or her own, it should not be approved.

#### 5. Independent Monitoring and Public Reporting

Every year a report should be made to provincial/territorial legislatures and to Parliament about the system. The report should include the number of requests, who requested and why. It should also include any alternatives that were put in place for a person, instead of dying.

#### 6. More Funding for Palliative Care, Disability and Community Supports

To make sure people have other options, governments must increase spending on palliative care and community supports for people with disabilities. This is the only way to make sure people have the option of inclusion in their community.

#### 7. Governments and Community Working Together

- The basics of the system need to be in laws at both the federal level and provinces and territories. Safeguards to protect vulnerable people should be in the federal *Criminal Code* to make sure the system is the same across the country.
- Governments must work together to design the system and make sure investments are made in palliative care and disability supports in the community. Without this, many people who may want to die, won't feel like they have a real choice to continue living.
- People with disabilities, older persons, and health care providers must all be included in designing and monitoring the system, because we believe 'nothing about us without us'.

The disability community was very concerned when the Supreme Court made physician-assisted suicide and voluntary euthanasia legal. We don't want people who are already vulnerable to become even more so.

Governments must put more funding into palliative care and community supports. Without that, we are concerned that people will choose to die through assisted suicide or voluntary euthanasia because they don't have another choice. We must make sure people with disabilities have real choices to live good lives in the community, secure and safe from harm, and able to live with dignity.

We urge governments and other stakeholders to think carefully in creating a system, to prevent outcomes that none of us want. We hope the system will promote choice, dignity and inclusion for all Canadians throughout their lifetimes. We think our proposals can help do that.

## Executive Summary

In *Carter v. Canada*, the Supreme Court struck down the *Criminal Code* prohibition on physician-assisted suicide and voluntary euthanasia. It directed that access must balance the right to choose with safeguarding vulnerable persons who may be induced to commit suicide.

For this purpose, we urge that the system for physician-assisted suicide and voluntary euthanasia be designed to fully account for growing vulnerability in Canadian society, including:

- Increasing prevalence and severity of disability, and multiple disadvantage
- Increasing prevalence of mental health difficulties and disability
- Lack of access to disability-related supports
- 70% gap in palliative care
- Poverty and labour force exclusion
- High rates of violence, abuse and insecurity for people with disabilities
- Barriers to health care access
- Rapid increase in cases of dementia
- High rates of depression among seniors in residential care
- Elder abuse

Our proposal, *Protecting Choice & Safeguarding Inclusion*, is guided by the United Nations *Convention on the Rights of Persons with Disabilities* and aims to ensure that:

**Adults may gain access to physician-assisted suicide or voluntary euthanasia only on the basis of real and informed choice. They must be free from abuse and vulnerability to lack of support, disrespect, discrimination and devaluation. The system must respect, promote and safeguard inclusion of all persons in society, regardless of their disability or other differences.**

### *Elements of the Proposed Plan*

- Core Values
- Principles and Guidelines
- Vulnerability Assessment in Informed Consent
- Advance Independent Review and Authorization
- Monitoring and Public Reporting
- Investment in Palliative Care and Community Supports
- Federal-Provincial/Territorial Jurisdiction, Investment, Coordination and Engagement

#### **1. Core Values**

The *Carter* decision states that a system for physician-assisted suicide and euthanasia must be guided by three core values: respect for autonomy, dignity, and preservation of life.

- To respect autonomy, the system must make sure that people really *are* making self-determined choices.
- To respect dignity, the system must be grounded on the two dimensions of this value. First, dignity is harmed when a person's autonomy is restricted, as the Court stresses in

*Carter.* Second, dignity is harmed when a person's social group is devalued and disadvantaged on the basis of shared characteristics, which is certainly the case for people with disabilities. Harming the dignity of whole groups can undermine autonomy because members of devalued groups often become socially and economically marginalized, lose a sense of self-worth, and feel a burden on society.

- To preserve life of people who may be vulnerable to being induced to commit suicide, the system must be designed to promote their inclusion in society, recognizing:
  - that the dignity of people with disabilities and older persons is harmed by the pervasive social and economic vulnerabilities of these groups; and
  - that the experience of indignity and vulnerability can, but not necessarily does, undermine autonomy of these persons.

We strongly believe that adequate safeguards for this purpose must include inquiry into whether conditions of vulnerability are affecting a person's choice for physician-assisted suicide or voluntary euthanasia.

## 2. Principles and Guidelines

The system should be designed, managed and accountable according to key principles of:

- real autonomy;
- understanding of conditions of vulnerability and harm to dignity;
- protection against inducement to commit suicide;
- engagement of persons with disabilities and their organizations in design and oversight.

Specific guidelines should include:

- informed consent on the basis of legal independence;
- disability, in and of itself, is not a grievous and irremediable condition;
- clinical input from at least two physicians;
- vulnerability lens and assessment applied in every case
- advance authorization by an independent review panel to consider: reasons, eligibility, timeliness, decisional capacity, and assessment of alternative courses of action;
- monitoring and annual reports to Parliament and provincial/territorial legislatures;
- provision for an expedited process to ensure compassion can be exercised in situations where criteria are clearly met and death is imminent or in the near future;
- distinguishing physician-assisted suicide and voluntary euthanasia from palliative care.

## 3. Vulnerability Assessment in Informed Consent

A 'vulnerability lens' must be applied in all cases. Where risk of vulnerability to inducement is identified, steps must be taken to explore and provide appropriate supports for people who may request assistance to die, but who are in fact vulnerable to being induced to commit suicide because of exclusion, devaluation and abuse.

A qualified assessor is needed to undertake a full vulnerability assessment and consideration of alternative courses of action, many of which will be of a community and social support nature. This exploration is beyond the mandate and training of physicians.

#### 4. Advance Independent Review and Authorization

Advance independent review and authorization of requests for physician-assisted suicide and voluntary euthanasia, along with an appropriate waiting period, is the only way to ensure that requests are not subject to undue influence or misapprehension. This will ensure:

- principles of autonomy, dignity and inclusion are applied in every case;
- adequate assessment of vulnerability and alternatives;
- decisions about whether to authorize or report a death are out of the hands of physicians;
- ongoing trust of family physicians by removing them from authorization of the interventions;
- an expedited process where warranted;
- protection against loosening criteria for eligibility.

#### 5. Independent Monitoring and Public Reporting

On an annual basis, independent review bodies in each province and territory should report on requests and outcomes to their respective legislatures, and a federal authority should report to Parliament.

#### 6. Needed Investment in Palliative Care, Disability and Community Supports

Increasing disability, entrenched poverty and a growing gap in palliative care and disability-related supports, means social vulnerability is growing. Requests for physician-assisted death and voluntary euthanasia may grow as a result. Governments must invest to close the gap in palliative care and disability supports so that Canadians have real choice and alternatives.

#### 7. Shared Jurisdiction, Investment, Coordination and Engagement

- *Federal Criminal Code amendments* – to mandate consistent standards across the country for eligibility, informed consent, vulnerability assessments, waiting periods, and advance independent review and authorization.
- *Provincial/Territorial Regulation* – to regulate access and advance authorization, independent review boards, health professions, health care services, vulnerability assessment, informed consent, adult protection, and legal capacity.
- *Coordinated Investment Strategy* – to ensure adequate and coordinated investment for palliative care and needed disability-related supports.
- *Government-Community Engagement* – to guide development, implementation and investment – with representation from health, disability and older person communities.

The disability community has been profoundly affected by the *Carter* judgment because of the risk it poses to advancing inclusion, equality and human rights for Canadians with disabilities. We hope our proposals help build common ground for a system that protects real choice and safeguards inclusion. We urge that foresight, caution, compassion and core values guide us all



in the exercise ahead so that the system will contribute to, rather than undermine, autonomy, dignity and inclusion for all Canadians throughout their lifetimes.

## Introduction

In its judgment in *Carter v. Canada*,<sup>1</sup> the Supreme Court struck down the *Criminal Code* prohibition on physician-assisted suicide and voluntary euthanasia in Canada where:

- A consenting adult has a grievous and irremediable medical condition that causes enduring suffering intolerable to that person; and
- The person is not vulnerable to being induced to commit suicide.

The Court stressed that a system to enable access to physician-assisted suicide and voluntary euthanasia must strike a balance between protecting the right to autonomy and dignity of individuals who make this choice, and protecting vulnerable persons in our society. The Court was clear that a “complex regulatory regime” was justified for this purpose, but that its design was better left to Parliament than the courts.<sup>2</sup>

In light of the *Carter* decision and the disability community’s longstanding concerns about assisted suicide, we have developed the proposal, *Protecting Choice & Safeguarding Inclusion*, to assist decision makers in designing a system.

Canada’s system will be the first in the world to be developed following the adoption of the United Nations *Convention on the Rights of Persons with Disabilities*, ratified by Canada in 2010. The global recognition of the systemic devaluation and disadvantage of persons with disabilities motivated this first international human rights treaty of the 21<sup>st</sup> century. Our proposed plan is guided by the *Convention* and proposes safeguards we believe would be most consistent with Canada’s obligations under the treaty. In particular, those obligations are to take necessary steps to respect and promote autonomy of persons with disabilities; protect the right to life on an equal basis with others; protect against exploitation, violence and abuse; and advance full inclusion in society.

In this regard, our proposed plan provides a means to safeguard inclusion in society for vulnerable persons, while at the same time respecting a decision to choose physician-assisted suicide or voluntary euthanasia because of an irremediable condition that causes enduring and intolerable suffering. Our plan aims to ensure that:

**Adults may gain access to physician-assisted suicide or voluntary euthanasia only on the basis of real and informed choice. They must be free from abuse and vulnerability to lack of support, disrespect, discrimination and devaluation. The system must respect, promote and safeguard inclusion of all persons in society, regardless of their disability or other differences.**

Significant challenges must be addressed if the system is to fully deliver on this outcome. We urge governments to proceed in a manner acutely aware of the risks, resolved to guard against outcomes none of us want, and committed to building an inclusive and accessible Canada where all are assured of autonomy, dignity and inclusion throughout their lifetimes.

In this report we reference both ‘physician-assisted suicide’ and ‘voluntary euthanasia’ to indicate that the scope of our proposal is restricted to these two interventions, as is the *Carter* decision. The Royal Society of Canada ‘Expert Panel on End-of-Life Decision Making’ defines these interventions as follows:

*“Assisted suicide” is the act of intentionally killing oneself with the assistance of another. “Voluntary Euthanasia” is an act undertaken by one person to kill another person whose life is no longer worth living to them in accordance with the wishes of that person.*<sup>3</sup>

## Why Do We Need a System to Protect Choice and Safeguard Inclusion?

People with disabilities, their families and representative organizations want to make sure a system for physician-assisted suicide and voluntary euthanasia offers real choice in end-of-life decision making. It must ensure that people who are vulnerable to being induced to commit suicide are not placed at risk of preventable death. Motivating our concerns are the widespread conditions of vulnerability experienced by Canadians with disabilities and older persons:

- ***Increasing prevalence and severity of disability, and multiple disadvantage*** – Almost 14% of the adult population in Canada has a disability and this prevalence rate is growing year by year. Women are over-represented in almost all age groups.<sup>4</sup> Among Aboriginal persons, the prevalence of disability is over 30%, with this higher rate due to significant environmental and trauma-related disabilities.<sup>5</sup> Overall there is an increasing prevalence of people with ‘severe’ or ‘very severe’ disabilities, currently estimated at 1.8 million adults in Canada.<sup>6</sup> This is a group particularly vulnerable to abuse, social exclusion, and stigma especially those multiply- disadvantaged by gender or ethno-racial-cultural status.
- ***Lack of access to disability-related supports*** – A growing gap in needed disability-related supports affects both people with disabilities and families. Statistics Canada reports that unmet need for support increases with severity of disability, with 49% of people with severe disabilities needing help or not receiving enough help. For people with disabilities not living alone, 80% rely on families for needed support. For those living alone, 56% rely on their families.<sup>7</sup> With the aging of the population this gap will grow substantially – because of increased disability prevalence and more limited capacity of aging family caregivers.
- ***Gap in palliative care*** – 70% of Canadians are not able to access palliative care,<sup>8</sup> which will become a growing issue as annual deaths increase from the current rate of 260,000 deaths per year to more than 425,000 per year by 2036.<sup>9</sup>
- ***Increasing prevalence of mental health difficulties*** – A study for the Mental Health Commission of Canada estimates 20% of Canadians experience mental health difficulties annually, including mood disorders, anxiety disorders, schizophrenia, attention

deficit/hyperactive disorders (ADHD), conduct disorders, oppositional defiant disorders (ODD), substance use disorders or dementia. It estimates that within a generation more than 8.9 million Canadians will be living with a mental illness.<sup>10</sup> Among people with disabilities who experience rates of violent victimization much higher than the general population, self-rated poor or fair health status, as well as sleep disorders and use of antidepressants or sedatives, are<sup>11</sup> associated at rates 50% to 90% higher than the average.

- ***Mental health disability and other disabilities co-related*** – Statistics Canada estimates there are over 1 million Canadians with mental health disabilities, which are defined for population surveys as a long-term condition that limits daily activities. Of this group, almost 92% also report having at least one other type of disability.<sup>12</sup>
- ***Poverty and labour force exclusion*** – Working-age adults with disabilities are about twice as likely to live in poverty as the general population (20.5% versus 11%). Almost 40% of Aboriginal persons with disabilities live in poverty. Persons with severe disabilities are multiply disadvantaged, with over 50% living in poverty. Employment rates are far lower for working age adults with disabilities (51.3%) than those without (75.1%). Among working age people with intellectual disabilities, labour force participation is only 30%.<sup>13</sup>
- ***Violence, abuse and insecurity***<sup>14</sup> – People with disabilities are twice as likely as non-disabled persons to be victims of violence. People with some form of cognitive or mental disability, including intellectual disability, are four times more likely to be victimized than those without. Women with disabilities are sexually assaulted at a rate at least twice that of the general population of women in Canada. Almost two thirds (65%) of violent crimes against persons with activity limitations were committed by someone who was known to the victim. Persons with disabilities are 2 to 3 times more likely to be victims of the most severe forms of spousal violence, including being sexually assaulted, beaten, struck or threatened with a weapon. It is estimated that 80% of psychiatric inpatients have been abused in their lifetimes.<sup>15</sup> Moreover, people with disabilities who are victims of violence are less likely than other victims to be satisfied with the police response and with the ability of courts to deal with the incidents in a timely manner. With the rate of sexual abuse experienced by Aboriginal persons with disabilities at five times the general population,<sup>16</sup> aboriginal persons with disabilities are particularly vulnerable.
- ***Barriers to preventive and acute health care*** – People with intellectual disabilities are three to four times more likely to die preventable deaths because of barriers to needed health care and other supports.<sup>17</sup>

Add to these factors the rapid aging of the Canadian population. This will mean a growing proportion of people with disabilities in the decades ahead and an increasing incidence of financial and other forms of abuse against persons with disabilities including older persons:

- **Rapid increase in cases of dementia** – The almost half a million Canadians with dementia in 2008 will increase 2.3 times by 2038 to over 1,125,000 individuals, at which point there will be 250,000 new cases diagnosed each year.<sup>18</sup>
- **High rates of depression among seniors** – The Canadian Institute for Health Information reports that over 40% of seniors living in residential care in Canada have either been diagnosed with depression or show symptoms of depression.<sup>19</sup>
- **Elder abuse** – Estimates of elder abuse prevalence range from 4-10% of the population, with financial abuse being the leading form.<sup>20</sup>

There is no doubt that conditions of vulnerability affect a large and growing proportion of Canadians with disabilities and older persons. With continued devaluation and discrimination on the basis of disability, and in the absence of needed social and health supports, recourse to physician-assisted suicide and voluntary euthanasia may well become more and more appealing to Canadians. That prospect should profoundly concern us all.

It is imperative that we learn from the historic disadvantage people with disabilities have faced, and also from progressive steps communities and governments are now taking to foster inclusion. These lessons can help inform design of a system to both protect real choice and at the same time safeguard social inclusion for vulnerable persons more generally.

Our Plan has seven main components:

- Core Values
- Principles and Guidelines
- Vulnerability Assessment in Informed Consent
- Advance Independent Review and Authorization
- Monitoring and Public Reporting
- Investment in Palliative Care and Community Supports
- Federal-Provincial/Territorial Jurisdiction, Investment, Coordination and Engagement

## 1. Core Values

In the opening paragraphs of the *Carter* decision, the Supreme Court of Canada asks how best to “balance competing values of great importance”:

*On the one hand stands the autonomy and dignity of a competent adult who seeks death as a response to a grievous and irremediable medical condition. On the other stands the sanctity of life and the need to protect the vulnerable.*<sup>21</sup>

Drawing on *Carter* and earlier decisions by the Court, we discuss below each of these values and point to key challenges and proposals for a system that appropriately balances them.

### *Autonomy – Freedom from Interference*

In *Carter* the Court states that respect for autonomy guards against “state interference with an individual’s physical or psychological integrity, including any state action that causes physical or serious psychological suffering.”<sup>22</sup> The court makes clear that “the right of medical self-determination is not vitiated by the fact that serious risks or consequences, including death, may flow from the patient’s decision.”<sup>23</sup>

Autonomy is a fundamental value in end-of-life decision making. In order to fully respect it, the system for accessing physician-assisted suicide or voluntary euthanasia must ensure that people really making truly self-determined choices. In other words, the system must be designed and managed in a way that ensures lethal interventions are provided only to individuals whose ability to independently choose the intervention has not been compromised in the circumstances.

What will guide the system in making this determination in any particular case? A full understanding of the value of dignity, a second value the Court identifies for guiding a legal framework, is an essential starting point.

### *Dignity – Valued Recognition of Individuals and Groups*

While the Court references ‘dignity’ many times in the *Carter* decision it does not define the term. However, in a number of other judgments the Court considers the value in some depth and points to the importance of protecting dignity for both individuals and groups. In a comparative analysis of the judicial interpretation of dignity in Canada and internationally, Christopher McCrudden references a number of these decisions. Many point to both individual and group dimensions of dignity.<sup>24</sup> In *Law v. Canada*, for example, the Court defines dignity as follows:

*Human dignity means that an individual or group feels self-respect and self-worth... Human dignity is harmed when individuals and groups are marginalized, ignored, or devalued, and is enhanced when laws recognize the full place of all individuals and groups within Canadian society.*<sup>25</sup>

In the more recent decision, *R. v. Labaye*, the Court found:

*Conduct or material that perpetuates negative and demeaning images of humanity is likely to undermine respect for members of the targeted groups and hence to predispose others to act in an antisocial manner towards them. Such conduct may violate formally recognized societal norms, like the equality and dignity of all human beings.*<sup>26</sup>

In *Carter*, the Court emphasizes the impact that denying a choice for assisted suicide can have on an individual’s experience of dignity, and quotes the trial judge in this regard: “She [the trial judge] further noted that seriously and irremediably ill persons were ‘denied the opportunity to make a choice that may be very important to their sense of dignity and personal integrity’ and that is ‘consistent with their lifelong values and that reflects their life’s experience’ (para.

1326).”<sup>27</sup> It is in large part this finding by the Court – that restriction of autonomy can undermine a person’s dignity – that leads it to conclude that banning access to physician-assisted suicide and voluntary euthanasia *entirely* cannot be justified.

The individual exercise of autonomy in relation to personal values and experience is one dynamic of dignity. Marginalizing, ignoring and devaluing *whole groups* on the basis of certain shared characteristics is another. In *Eldridge*, the Court gives this latter dimension significant attention with respect to people with disabilities in particular:

*It is an unfortunate truth that the history of disabled persons in Canada is largely one of exclusion and marginalization. Persons with disabilities have too often been excluded from the labour force, denied access to opportunities for social interaction and advancement, subjected to invidious stereotyping and relegated to institutions... This historical disadvantage has to a great extent been shaped and perpetuated by the notion that disability is an abnormality or flaw. As a result, disabled persons have not generally been afforded the “equal concern, respect and consideration” that s. 15(1) of the Charter demands.*<sup>28</sup>

There is an extensive literature to support the claim that how social groups are known and recognized in society directly shapes the extent to which members of those groups experience dignity.<sup>29</sup> To the extent that a social group is valued on the basis of shared characteristics, members of that group experience dignity. When a group is devalued on the basis of certain characteristics – like perceived “abnormality or flaw” in the words of the Court in *Eldridge* – members of that group can experience harm to their dignity because of how they are viewed, known and stigmatized by others.

Concern for the ways in which denial of autonomy can undermine dignity is one side of the dignity/autonomy coin and the Court rightly considers it in *Carter*. Concern for the ways in which *harming dignity can undermine autonomy* is the other. How does this happen? The research shows that among the most prevalent reasons for requesting assisted suicide, including an “individual’s need for control over the illness and his or her body/life, a desire not to be a burden on others, and depression and psychological distress often associated with illness”,<sup>30</sup> disability-related conditions figure prominently. We should be acutely concerned that these reasons predominate in a context, outlined above, of growing prevalence of disability in our society; the enormous scale of depression among seniors living in residential care; the link between mental health-related disability and other types of disability; the lack of needed disability-related support and palliative care; and, the extent of financial and other abuse against people with disabilities and older persons.

Given the context of systematic harm to the dignity of persons with disabilities, it is not surprising that individuals with disabilities themselves, along with their family members, health professionals and community members more generally, can come to see their lives as not worthy of living to the same extent as other lives. When others use characteristics similar to

one's own as a reason to die or as an indicator of a life not worth living (for example growing physical and cognitive dependence on others which may constitute psychological suffering for some), community support for our unique developmental path can diminish. Valued social recognition and a person's sense of self-worth and self-esteem can be threatened in such an environment and contribute to the vulnerability of persons who live with these characteristics. Indeed, evidence shows how suicidal ideation figures predominantly among people with disabilities both in initial response to onset of disability and in response to lack of access to needed community supports.<sup>31</sup>

For some, the option of accessing physician-assisted suicide or voluntary euthanasia may be appealing because of concern about the financial, emotional and caring burden on a family if a person continues to live for many more months or years to come. This calculus could become more and more compelling, especially as demands on health care and community support services grow. Continuing to live under such circumstances may come to be seen by some as either a selfish act or as an unnecessary drain on publicly-funded health and social supports, and on family caregivers. With these conflicting perspectives already in play, introduction of a system may well sow the seeds for relational harms, making the social environment of a person with a disability that much more vulnerable and both the desire and the decision to continue living that much more untenable.

The Royal Society of Canada's Expert Panel on End-of-Life Decision Making recognized the risk of relational harm, for both individuals and at a "macro" level, which assisted suicide and voluntary euthanasia could engender:

*Relational harms are very much at issue in cases of assisted suicide and voluntary euthanasia not only at the micro level in terms of the relationships of particular parties (health care professional - patient, between family members, etc.), but also at a macro level in terms of the potential harm to broader social values (respect for autonomy, life, etc.).*<sup>32</sup>

The Panel considered this risk in a context where the interventions remained a violation of the law. However, we are not convinced that individual relationships and broader social values will not be harmed simply because the interventions are legalized. Individual patients, their families, friends and health professionals will be just as torn in the decision-making process, if not more so, when legal access is provided.

To the extent that personal, social and institutional forms of reasoning outlined above become more widespread, they will contribute to, and more deeply entrench, an already negative social construct of disability. Negative constructs of disability contribute to further disabling people and embedding discrimination because of how they shape social perception. Indeed, the Supreme Court recognized in *Mercier* that a "handicap" may result from "a physical limitation, an ailment, a social construct, a perceived limitation or a combination of all of these factors."<sup>33</sup> With the growing proportion of people with cognitive, psychosocial, intellectual and/or physical



disabilities that we see on the horizon, these forms of reasoning risk reproducing negative constructs and social perceptions, further threatening social cohesion and solidarity with these groups.

This is not to suggest that people with disabilities, by definition, are unable to fully exercise autonomy in end-of-life decision making. Such an assumption would perpetuate negative social constructs and systemic devaluation. It is simply to caution that careful consideration must be given in designing safeguards. Protocols must be in place to ensure that a person's dignity has not been so harmed by personal and systemic devaluation and lack of access to needed support that for that person, no other option but physician-assisted death or voluntary euthanasia seems possible. In designing protocols to protect and promote dignity as the basis for autonomy in these circumstances, questions to be addressed include:

- What steps can be taken to ensure that access is carefully considered, and possibly overridden, in those situations the Court states the law should provide for – when people are vulnerable to being induced to commit suicide?
- How can the system assure itself that a person's dignity has not been so undermined by systemic devaluation and lack of access to needed support that his or her exercise of autonomy is too compromised in the circumstances to justify approving a request?
- What steps can be taken to explore alternative courses of action that address devalued status and lack of supports, and when and how is that exploration process triggered?
- How can the system contribute to a culture that promotes social inclusion, solidarity and cohesion that makes living with disability something to be valued in society, rather than in any way denigrated?

To answer these questions it is helpful to draw on the third value that the Court states should be balanced in regulating access to physician-assisted suicide and voluntary euthanasia – the sanctity and preservation of life.<sup>34</sup> The Court finds that this value underlies the valid objective of the prohibition, to protect vulnerable persons from being induced to commit suicide. We characterize this value as the value of 'inclusion.' For persons with a disability their vulnerability, and often the very preservation of their lives in situations of abuse, is directly related to the extent to which they are supported to be included in trusting and caring relationships, and also have meaningful access to, and participation in, the community more generally.

### *Inclusion – Community Support, Access and Participation*

Article 10 of the UN *Convention on the Rights of Persons with Disabilities*, on the 'Right to Life', states:

*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.*

We suggest that the value of protecting and preserving sanctity and right to life of persons with disabilities and older persons who may be vulnerable in the context of a system for physician-assisted suicide and voluntary euthanasia, should be understood as safeguarding the value of inclusion.

In the course of a lifetime most of us build up a personal supply of assets which provide resilience to vulnerability and that keep us safe, barring unforeseen circumstances. However, this is often not the case for people who experience systemic disadvantage.<sup>35</sup> Assets that help reduce vulnerability are also indicators of inclusion:

- having a job or other income;
- having an education;
- having a safe and comfortable place to live;
- having the supports that we need;
- having family and friends who care about us;
- being valued and respected in our communities.

Through a series of cases decided under the *Charter of Rights and Freedoms* the Supreme Court of Canada has evolved an understanding of equality as full inclusion in society.<sup>36</sup> Central to the Court's understanding is the importance of full participation in, and meaningful and equal access to, education, the workforce, transportation and other services and opportunities generally available to the public.<sup>37</sup> In a recent judgment, in relation to access to education the Court found that "meaningful access" is the key:

*... if the evidence demonstrates that the government failed to deliver the mandate and objectives of public education such that a given student was denied meaningful access to the service based on a protected ground, this will justify a finding of prima facie discrimination.*<sup>38</sup>

When people with disabilities are included in society in this manner, the conditions of their vulnerability are ameliorated. In this regard, the Law Commission of Ontario defines the principle of 'social inclusion and participation' as it applies to persons with disabilities as follows:

*This principle refers to designing society in a way that promotes the ability of all persons with disabilities to be actively involved with their community by removing physical, social, attitudinal and systemic barriers to exercising the incidents of such citizenship and by facilitating the involvement of persons with disabilities.*<sup>39</sup>

Research on vulnerability suggests that it is not only the lack of access, support and participation that makes people with disabilities vulnerable. It is often the dependent position

people are placed in, in relation to their support providers. The ARCH Disability Law Centre reports on how this dynamic can threaten the status of persons with disabilities:

*[t]his dependence leaves people with disabilities vulnerable; they must work hard to maintain good relationships with support workers, family members and others on whom they rely in order to ensure that they continue to receive support and their basic needs are met. Making a complaint about a support worker or raising a concern about services may threaten or sever those relationships, and this can have disastrous impacts for the person with a disability.<sup>40</sup>*

Inquiry into the conditions of vulnerability and consideration of alternative courses of action that would maximize inclusion will be necessary in some cases to determine if the request is in fact an autonomous choice that respects and promotes a person's dignity. The principle of autonomy as freedom from interference must certainly be protected in the system. At the same time, given what is at stake for a person and for society in ensuring that vulnerable persons are indeed protected, a role for state intervention is justifiable when it appears that vulnerable persons may not be able to fully exercise autonomy in making a request or are being induced to make the request.

Legal scholar, Martha Albertson Fineman, suggests that the existence of vulnerability provides a clear foundation for state intervention and oversight to address its conditions:

*The nature of human vulnerability forms the basis for a claim that the state must be more responsive to that vulnerability. It fulfills that responsibility primarily through the establishment and support of societal institutions. Additionally, those institutions are themselves vulnerable to a variety of internal and external corruptions and disruptions, and this realization is the basis for the further claim that these institutions must be actively monitored by the state in processes that are both transparent and inclusive.<sup>41</sup>*

## 2. Principles and Guidelines

The pillars of a proposed system are outlined in the following principles and guidelines.

### *Fundamental Principles*

1. Real autonomy in choosing physician-assisted suicide and voluntary euthanasia must include consideration of alternative courses of action.
2. People are made vulnerable as a result of social or economic circumstances that diminish their resiliency. Conditions such as poverty, isolation, discrimination, devaluation and lack of needed supports are therefore highly relevant in determining whether a person may be vulnerable to inducement.

3. Persons who are vulnerable to being induced to commit suicide in times of weakness must be protected, their conditions of vulnerability anticipated and adequately responded to.
4. Persons with disabilities and their representative organizations have much at stake in the design, delivery and evaluation of any system developed to protect persons who are vulnerable to being induced to request physician-assisted suicide and voluntary euthanasia.

### *Guidelines for Legislative and Policy Response*

1. Assisted suicide must be available only to adults who are able to act legally independently and with a grievous and irremediable condition that is the cause of enduring suffering that is intolerable to the individual. 'Legal independence' for the purposes of health care, property and personal decisions has been defined as a person's ability "by him or herself or with assistance, to understand information that is relevant to making a decision; and... the ability, by him or herself or with assistance, to appreciate the reasonably foreseeable consequences of a decision."<sup>42</sup>
2. In and of itself, disability is not a grievous and irremediable condition.
3. Requests for physician-assisted suicide and voluntary euthanasia must be reviewed and authorized by an independent review panel, with sufficient information to determine if the necessary criteria are met. This review must occur prior to any approved actions causing a person's death.
4. In making its decision the review panel must consider the following information:
  - a. The person's request and reasons for the request;
  - b. A clinical evaluation by a qualified physician regarding whether the person meets the medical criteria;
  - c. A clinical evaluation by a qualified physician regarding whether the person's condition is irremediable in the sense that it is likely to cause death within the foreseeable future. Where this prognosis is not the case, special inquiry must be made into whether there are conditions that place the person at risk of being vulnerable to being induced to commit suicide, and whether all alternative courses of action have been considered;
  - d. An evaluation by a qualified physician that the person is competent to make the decision;
  - e. An assessment of whether the person's request is informed and voluntary;
  - f. An assessment of potential alternative courses of action that might reduce the person's suffering. This assessment must be conducted by a qualified professional in consultation with the patient, and must address a full range of alternatives to

- physician-assisted suicide and voluntary euthanasia including medical treatment, palliative care, counselling and disability-related supports;
- g. Submissions by third parties with direct knowledge relevant to the request, subject to the discretion of the review panel;
  - h. The length of an appropriate waiting period in the circumstances to ensure the person has adequate time to consider alternative courses of action, as may be needed;
  - i. Any need for an expedited process to ensure compassion can be exercised where criteria are clearly met and death is imminent or in the near future.
5. Clinical input to the review panel must come from at least two different physicians.
  6. A monitoring system and annual public reports to Parliament and provincial/territorial legislatures must be in place to track and report on:
    - a. the number of requests;
    - b. the reasons given;
    - c. medical condition, socio-economic circumstances and demographic factors associated with persons making requests, and those whose requests are authorized or denied;
    - d. availability and acceptance or refusal of alternative courses of action identified;
    - e. efficacy of alternative interventions including access to medical treatment and palliative care;
    - f. outcome of requests authorized and denied.

These principles and guidelines are designed to help legislators, policy makers and regulators achieve the right balance between dignity, autonomy and inclusion. They are informed by an inclusive vision of ethics and law and are designed to ensure that real choice is made available to persons considering physician-assisted suicide and voluntary euthanasia. By definition, real choice in this case must include consideration of alternative courses of action to the intervention.

Advance independent review and authorization of the decision is also an essential mechanism for ensuring real choices are provided so that autonomy can in fact be exercised. This will help to ensure that the foundations of inclusion – equal respect and support for different developmental pathways, including those identified as disabled – are fostered and remain intact. Finally, the guidelines point to a need for monitoring and public reporting to ensure transparency and guide ongoing evaluation and adaptation of the system as may be needed to ensure compliance with underlying values, principles and guidelines.

### *Distinguishing Physician-assisted Suicide and Voluntary Euthanasia from Palliative Care*

Our proposal is also based on clearly distinguishing physician-assisted suicide and voluntary euthanasia from palliative care. We strongly urge that physician-assisted suicide and voluntary euthanasia not be considered one of the options in a palliative care system. We also urge that patients who are receiving palliative care and decide to choose physician-assisted suicide or voluntary euthanasia are not abandoned by the palliative care system. Obligations must be in place to ensure that patient autonomy is respected, while at the same time not requiring health care providers to fundamentally alter their provision of services.

Distinguishing physician-assisted suicide and voluntary euthanasia from palliative care rests on the difference between intent and foresight, as legal scholar John Keown has forcefully argued in his systematic critique<sup>43</sup> of the reasoning in the *Carter* decision handed down by Justice Lynn Smith of the British Columbia Supreme Court.<sup>44</sup> While administration of pain management may be done in palliative care, for example, with the foresight that death will eventually come, death is not the intent of the intervention. In physician-assisted suicide and voluntary euthanasia, on the other hand, bringing about death is the intention and a chemical regime is administered for this purpose. We strongly recommend that in order to protect the ethics and integrity of palliative care that these distinctions remain in clear view.

## 3. Vulnerability Assessment in Informed Consent

### *Assessing Vulnerability*

The Supreme Court stresses numerous times in the *Carter* decision that a system for access to physician-assisted suicide and voluntary euthanasia must include measures to protect vulnerable persons from being induced to commit suicide in a time of weakness. When the causes of people's suffering are abuse, discrimination, being devalued by others, lack of support or social isolation, steps can be taken to address them. As well, when people are disabled as a result of traumatic injury or illness, suicidal thoughts often come in early stages of recovery and/or care.

The system for physician-assisted suicide and voluntary euthanasia must be sensitive to these risks and include mechanisms to assess their impact on autonomous choice. Therefore, it must be structured to identify and assess possible vulnerability factors and facilitate exploration of, and access to, appropriate supports for people who request assistance to die. Factors to address in a vulnerability assessment should include:

- Poverty and lack of needed care and support;
- Social isolation;
- A sense of being a burden on others;
- Experience of growing dependence on others and a loss of control;
- Denial of rights or social stigma which leads to experience of disrespect and devaluation;

- Abuse and intimidation by others who stand to financially or otherwise benefit from the person's death;
- Encouragement from others that promise that true dignity and nobility will come as a result of their choice of death.

We recommend mandatory application of a 'vulnerability lens' at three points, namely: where a person makes a request for physician-assisted suicide and voluntary euthanasia; during the process of considering alternatives; and, at the stage of advance independent review and authorization. This is necessary to ensure that potentially vulnerable people are identified and safeguarded by the system, as required under the law. As required under the *Carter* decision, where significant vulnerability to inducement is identified, physician-assisted suicide or voluntary euthanasia cannot be the first recourse, even if requested. Alternative courses of action must be facilitated.

However, the system should not require detailed assessment of vulnerability when it is clear that a person meets the criteria as laid out in *Carter*, death is imminent or foreseeable in the near future, suffering is enduring and intolerable and the decision is clearly informed and voluntary. Compassion is paramount in these situations and the system should be designed to ensure that the decisions can be expedited and carried out after any appropriate waiting period.

### *Informed Consent Process*

Given the widespread conditions of vulnerability among Canadians with disabilities and older persons, and given the gravity of the decision under consideration, a process for exploring alternative courses of action to physician-assisted suicide and voluntary euthanasia, including palliative care, must be provided for in the consent process.

Exploring alternative courses of action is a well-established and legally-recognized step in the informed consent process. For example, Ontario's *Health Care Consent Act* stipulates in s.11(2) that "A consent to treatment is informed if, before giving it, the person received the information about the matters set out..." which include information about "alternative courses of action."<sup>45</sup>

It is important to recognize that exploring alternatives to the social and economic conditions of vulnerability which place people at risk of being induced to commit suicide in times of weakness is likely beyond the capacity of family or specialist physicians. Many alternative courses of action in relation to standard health care decisions are within the scope of a physician's expertise, including palliative care and pain management. However, considerations of psychological suffering, vulnerability and inducement are not usually part of their expertise or training so it is appropriate that these be explored by a professional with more knowledge and training in these non-medical considerations.

As well, it is important to note that considerations of coercion, undue influence, pressure and exploitation of inequality particularly in the context of intimate and confidential relationships, are not usually considered in health care decisions. However, precedent exists for consideration of these factors, along with decisional capacity, in other areas of law, for example, testamentary capacity in relation to the making of wills.<sup>46</sup> The informed consent process for physician-assisted suicide and voluntary euthanasia must be adapted to ensure these factors are adequately considered, and that any vulnerability to inducement can be ruled out.

Given these considerations, gathering information about possible undue influence and suspicious circumstances, and any alternatives in the person's family and community social support system, will require assistance of qualified assessors. We recommend the following approach be taken to ensure truly informed consent is obtained, as required by law:

- Alternative course of action be assessed by a qualified assessor in every case where a request for physician-assisted suicide and voluntary euthanasia is made to a responsible physician, and where the physician makes an initial determination that person making the request has the decisional capacity to act legally independently;
- Qualified assessor explores alternatives with the patient and ensures the patient is aware of options, and assisted to pursue any chosen options;
- Qualified assessor sends report to responsible physician and independent review board;
- If, after the assessment, the patient continues to request physician-assisted suicide and voluntary euthanasia, the responsible physician ensures that the patient is giving 'informed consent' and has the decisional capacity to do so;
- Referral is then made for consideration by an independent review.

Without proactive measures and a process for considering a range of alternative courses of action, real choice and informed consent are simply not possible for many people with disabilities. To be given the option for physician-assisted death or voluntary euthanasia without such consideration would be inconsistent with law, discriminatory and would demonstrate a lack of compassion. It would represent the denial of the life, liberty and security of the person. The process must provide full scope for identifying vulnerability and providing alternatives.

We recognize there will be a small number of extremely difficult situations where individuals are experiencing suffering of such an extent that they make a request for physician-assisted suicide and voluntary euthanasia where alternatives are either extremely limited or do not exist at all. To require a person to undergo extensive vulnerability assessment in these circumstances would neither be compassionate or respectful of their autonomy and dignity. In such situations, any assessments must be sensitive to the timeliness required, the suffering involved and a reasonable scope of options in the circumstances.



### *Determining Decisional Capacity*

The Supreme Court emphasizes that one of the criteria to obtain physician-assisted suicide and voluntary euthanasia is that the person be a competent adult, which it states means having decisional capacity as can usually be determined by a physician. There is a growing recognition, however, that determining decisional capacity is not a straightforward matter, especially with the growing proportion of older persons in the population and often associated cognitive decline. As well, the United Nations *Convention on the Rights of Persons with Disabilities* has a bearing on an emerging understanding of ‘supported decision making’ capacity. It recognizes in Article 12 that persons cannot be discriminated against in the exercise of legal capacity, on the basis of mental or physical disability, including for health-related decisions, and that state parties have an obligation to ensure people have access to the supports they may require to exercise their decisional capacity.

All of this means that it may be impossible to draw a ‘bright line’ between those who have capacity to make the decision to have physician-assisted suicide and voluntary euthanasia, and those who do not. This makes it especially important to ensure that persons are free of vulnerability to inducement in making this life-ending decision.

While jurisprudence on decisional capacity and competence points increasingly to the legal obligation to recognize supports in decision making, we propose that a legislative line be clearly drawn. A report for the Law Commission of Ontario recommends that for the purposes of decisions that may fundamentally affect a person’s mental or physical integrity, of which physician-assisted suicide and voluntary euthanasia is one, the law require that the person be able to act ‘legally independently’ (as defined in the proposed Guidelines above). That is, a person *on his or her own* must be able to fully understand and appreciate the nature and consequences of the decision, with supports and accommodations as may be required for this purpose.<sup>47</sup>

The report also recommends that health care and decision-making statutory law provide for identifying decisions which must be made *exclusively* in this manner, and which we would recommend must also include physician-assisted suicide and voluntary euthanasia. This would mean that persons who require extensive supports to make decisions, and who thus do not meet the test of legal independence, could not be considered to have the decisional capacity to consent to physician-assisted suicide or voluntary euthanasia.

## **4. Advance Independent Review and Authorization**

The need for independent review and oversight in physician-assisted suicide and voluntary euthanasia has been recognized in international law to be an essential safeguard in ensuring respect for the inherent right to life. More than once, the United Nations Human Rights Committee has called on the Netherlands, where physician-assisted suicide is recognized in law and can be authorized by two physicians, to provide for independent review in order to

“guarantee that this decision was not the subject of undue influence or misapprehension.”<sup>48</sup> The Committee justifies the need for “independent review by a judge or magistrate” because of the potential for violation of the “inherent right to life” as recognized in Article 6 of the *International Covenant on Civil and Political Rights*, ratified by Canada in 1976.

Our proposal is for *advance* independent review and authorization of requests for physician-assisted suicide and voluntary euthanasia, along with an appropriate waiting period. We believe this is the only way to ensure that the decision is, in fact, ‘not the subject of undue influence or misapprehension.’ This must be combined with an appropriate waiting period after the initial request is made, in order to ensure there is opportunity to re-consider the request and any alternative courses of action that may be identified in the interval.

Without advance independent review and an appropriate waiting period, the risk of vulnerability to inducement cannot be adequately assessed. Advance information required should include: the reasons given for the request, the medical condition, socio-economic circumstances, demographic factors, decisional capacity, results of the vulnerability assessment, and information on availability and acceptance or refusal of alternative courses of action identified, including palliative care. Efficacy of alternative interventions in withdrawing requests should also be reported.

The ‘check and balance’ of an advance independent review and authorization has a number of positive features:

- Ensures that adequate assessment about vulnerability and alternative courses of action has been undertaken;
- Takes any equivocation about whether to authorize or report a physician-assisted suicide and voluntary euthanasia out of the hands of physicians, and thereby addresses the well-documented issue of physicians not reporting assisted deaths,<sup>49</sup> evident in all jurisdictions with systems now in place;
- Ensures that trusted family physicians are not placed in the position of authorizing interventions intended to cause death, although they may be asked to carry out that intervention and may choose to do so once authorized;
- Ensures that the principles of dignity, autonomy and inclusion are applied in every single case, and that potential for relational harm is considered;
- Provides for an expedited process where warranted;
- Helps protect against loosening the interpretation of the Court’s criteria for eligibility that could come in practice without such oversight, and thereby deters from the slippage now being seen in other jurisdictions.<sup>50</sup>

It is simply not possible for one physician or two physicians to manage these needed checks and balances. Physicians should determine capacity to decide and, with the help of a qualified assessor, determine whether there is evidence of vulnerability to being induced to commit suicide. An advance independent review and authorization body can assess this evidence and

also determine whether the inherent right to life has been adequately protected in the circumstances in order to maximize social inclusion.

This 'division of labour' and system of checks and balances would help build trust in the system, assuring that where reasons for physician-assisted suicide and voluntary euthanasia seem suspect, or where they are rooted in negative stereotypes and stigma about a life presumed not worth living, that pause in the decision-making process could be afforded. Additional evidence could be called for, and a deeper assessment of vulnerability could be undertaken if required

Some have suggested that the safeguards in jurisdictions which have implemented physician-assisted suicide and voluntary euthanasia, largely consisting of review and approval by two physicians, are sufficient. Margaret Battin, et al., for example, suggest that such systems are adequate to protect the vulnerable and avoid abuse, although the authors indicate that the evidence is not conclusive. Moreover, they arrive at their assessment on the basis that fewer elderly persons, for example, chose assisted death than those in the 18-64 range, fewer women than men, fewer of those with lower socio-economic status than higher, etc. While these may be standard categories of vulnerability, the data tell us nothing about whether people who chose physician-assisted suicide and voluntary euthanasia experienced the vulnerability that comes with a sense of losing independence, diminishing capacity, feeling a burden on others, or social isolation. In fact, the evidence shows substantial increase in physician-assisted suicide and voluntary euthanasia in jurisdictions where it has been legalized (an increase in Belgium, for example, of over 550% between 2002 and 2009),<sup>51</sup> and authorized precisely for these kinds of reasons, underlying which are often negative stereotypes based on disability.

We firmly believe that Canada's obligations under the UN *Convention on the Rights of Persons with Disabilities*, in particular Article 10 on the 'Right to life' and Article 16 on 'Freedom from exploitation, violence and abuse' require an *advance* review and authorization of physician-assisted suicide and voluntary euthanasia. The *Convention* is based on a recognition of the scale of disability-based exploitation, violence and abuse that occurs in Canada (as the demographic overview at the outset demonstrates) and in other countries around the world. The obligations outlined in Article 16 require the kinds of investigation and interventions we are recommending for vulnerability assessment and advance review and authorization. As stated in Article 16:

1. *States Parties shall take all appropriate legislative, administrative, social, educational and other measures to protect persons with disabilities, both within and outside the home, from all forms of exploitation, violence and abuse, including their gender-based aspects.*
2. *States Parties shall also take all appropriate measures to prevent all forms of exploitation, violence and abuse by ensuring, inter alia, appropriate forms of gender- and age-sensitive assistance and support for persons with disabilities and their families and caregivers, including through the provision of information and education on how to*

*avoid, recognize and report instances of exploitation, violence and abuse. States Parties shall ensure that protection services are age-, gender- and disability-sensitive.*

*3. In order to prevent the occurrence of all forms of exploitation, violence and abuse, States Parties shall ensure that all facilities and programmes designed to serve persons with disabilities are effectively monitored by independent authorities.*

*4. States Parties shall take all appropriate measures to promote the physical, cognitive and psychological recovery, rehabilitation and social reintegration of persons with disabilities who become victims of any form of exploitation, violence or abuse, including through the provision of protection services. Such recovery and reintegration shall take place in an environment that fosters the health, welfare, self-respect, dignity and autonomy of the person and takes into account gender- and age-specific needs.*

*5. States Parties shall put in place effective legislation and policies, including women- and child-focused legislation and policies, to ensure that instances of exploitation, violence and abuse against persons with disabilities are identified, investigated and, where appropriate, prosecuted.*

While provisions for advance review and authorization are clearly required, in the interests of compassion we again want to stress that this process should not be onerous where it is not warranted. As with the process for assessing vulnerability outlined above, the review should be extremely sensitive and adaptive to the need for timely decisions. There should be provision for an expedited process where a person has made a clear request, provided informed consent, extensive vulnerability assessment and consideration of alternatives is obviously redundant, death is imminent or near and suffering is enduring and intolerable in the circumstances. Experience with independent review mechanisms such as the Ontario Consent and Capacity Board demonstrate that such mechanisms can render very timely decisions as may be needed.

## **5. Independent Monitoring and Public Reporting**

A monitoring system and annual public reports to Parliament and provincial/territorial legislatures is essential for an effective system for regulating access to physician-assisted suicide and voluntary euthanasia. Ultimately, legislative bodies must be able to determine if the parameters of the safeguarding system are sufficient to protect the right to life and inclusion, while respecting real choice and the principle of dignity for all persons and groups.

In order to deliberate on this question, policy makers and legislatures must have reliable information on the functioning of the system. Independent bodies to provide advance review and authorization can facilitate valid and reliable information sources for monitoring purposes. In addition to the information provided as part of the requests, physicians administering approved physician-assisted suicide or voluntary euthanasia should also be required to report to the independent bodies on the time and outcome of the administration, any variance in decisions once authorized, and confirmation that informed consent was obtained. With all this

information, the independent bodies will be able to report on requests made, those authorized and denied, and the outcome of those requests in either case.

A federal authority should be established to work with provincial/territorial governments in developing consistent protocols for gathering information. Independent review bodies in each province and territory should be charged with annual reporting to their respective legislatures, and the federal authority should also report annually to Parliament with a national picture based on this information.

## 6. Needed Investment in Palliative Care, Disability and Community Supports

As noted, there are well-documented gaps in access to palliative care, with estimates that 70% of Canadians are not able to access care they need.<sup>52</sup> As the Quality End-of-Life Care Coalition of Canada notes, this will become a growing issue with the expected deaths per year in Canada to increase from the current approximately 260,000 deaths per year to more than 425,000 per year by 2036.<sup>53</sup> As the Coalition also indicates: “Despite the fact that most Canadians would prefer to die at home, surrounded by their loved ones, most are still dying in hospitals or long-term care homes.”<sup>54</sup>

At the same time, there is an extensive gap in needed disability supports affecting both people with disabilities and families, with Statistics Canada reporting unmet needs for help for 49% of people with severe disabilities, and 80% of those not living on their own relying on families for care.<sup>55</sup>

With rapid aging of the population and increase in disability prevalence, entrenched poverty of people with disabilities, the hugely disproportionate rates of violent victimization and abuse of persons with disabilities, and the growing gap in need for palliative care and disability-related supports, the stage is set for social vulnerability to grow exponentially over the next few decades. It is in the context of a federal-provincial/territorial policy vacuum to meet the current and anticipated scale of need and a completely inadequate patchwork system of community supports that requests and support for physician-assisted suicide and voluntary euthanasia has grown in the past twenty years. Without needed investments and safeguards, they will grow substantially in years to come.

We must make certain that physician-assisted suicide and voluntary euthanasia in Canada does not become a choice of individuals and families by default: the only way to re-gain some sense of control over one’s life and end the sense of burden on others that result from a lack of other options. This is not a calculus Canadians should be forced to make.

Governments must step up to ensure that Canadians have real choice and alternative courses of action, even in situations of irremediable medical conditions and the experience of profound suffering. We believe there can *always* be alternatives – not that individuals should be forced

to choose them – provided we make the political, fiscal and policy decisions to make them available.

## 7. Federal-Provincial-Territorial Jurisdiction, Investment, Coordination and Engagement

A system for regulating physician-assisted suicide and voluntary euthanasia in Canada should be established through a coordinated federal-provincial/territorial framework. Both levels of government have roles to play. We propose broad outlines for the roles of each level of government below.

### *Criminal Code Amendments*

In order to balance the principles of dignity, autonomy and inclusion, the Supreme Court determined that the ban on assisted suicide must remain in place in the *Criminal Code* in order to protect persons who are vulnerable to being induced to commit suicide. As such, amendments to the *Criminal Code* are required to ensure clear and consistent standards across the country, with clear parameters for criminal violation. Provisions in the *Code* should address: eligibility criteria for access; the requirements for legal independence in informed consent; requirement of vulnerability assessments; the waiting period; and the mechanism for advance independent review and authorization of requests.

We strongly support the recommendations for *Criminal Code* amendments in this regard as proposed by David Baker and Gilbert Sharpe,<sup>56</sup> and also the associated recommendation of the Royal Society of Canada Expert Panel of End-of-Life Decision Making, which states:

*The Criminal Code is the best available mechanism for legal reform for a number of reasons. First, as it flows from the federal Parliament, it provides for the greatest consistency of approach across all of the provinces and territories. There is merit in treating an issue of such extraordinary social significance grounded in constitutional values as consistently across the country as possible. Second, again, as it flows from the federal Parliament, it allows for the creation of a national oversight body that could ensure an accurate and comprehensive picture of what is happening in the area of assisted suicide and voluntary euthanasia across the country. This would be efficient, protective, and reassuring as well as in line with best international practice.<sup>57</sup>*

*Criminal Code* requirements for an independent body for advance review, authorization and monitoring at the provincial/territorial level could be modeled on, or be an expanded version of, the provincial/territorial Review Boards currently required under the *Code*. Alternatively, the *Criminal Code* could set out requirements for such authorities and provincial/territorial governments could establish or adapt such administrative boards as currently exist, for example the Consent and Capacity Board in Ontario.

### *Provincial/Territorial Regulation of Informed Consent, Vulnerability Assessment and Health Professions*

The legislative, policy and program framework for informed consent, vulnerability assessments, and procedural requirements for advance independent review and authorization must also be recognized and regulated by statute in provincial/territorial jurisdictions. A regulatory framework for health professions and the delivery system for acute and community-based health services, mental health care and palliative care will need to be established in order to ensure appropriate delivery, consistent with *Criminal Code* requirements. Associated law reform in health care, informed consent, adult protection and legal capacity will be required in order to protect real choice and autonomy and to safeguard social inclusion for vulnerable persons.

### *Coordinated Investment Strategy*

There is real risk that physician-assisted suicide and voluntary euthanasia will become policy choice by default, and attractive to both individuals and governments because of collective failure to adequately invest in needed health and social supports and palliative care. We urge federal and provincial-territorial governments to guard against this outcome, and to take early and coordinated preventive action. Both levels of government must come up with the fiscal mechanisms to ensure adequate and coordinated investment, and shared guidelines for policy and program development associated with that investment.

### *Government-Community Engagement*

We also urge the federal and provincial/territorial governments to establish a coordinated process to guide development, implementation and monitoring of the system and the investment strategy for health and social supports and palliative care. The first priority should be developing draft legislation and policy for both levels of government. A standing federal-provincial/territorial table should be established for this purpose. It should bring together officials from relevant departments of justice and health and social services, and proactively engage representatives of health professions, and the disability and older person communities.

## Conclusion

The Supreme Court of Canada has placed Canadian society at a crossroads. Despite extremely polarized views on the morality, ethics and law of physician-assisted suicide and voluntary euthanasia, Canada will go down this path effective February 6, 2016 or shortly thereafter.

Physician-assisted suicide or voluntary euthanasia is a final and irreversible intervention for a person, a family, loved ones, those administering the intervention with the intent to cause death, and the community as a whole. We must make certain that in every case, real autonomy is being exercised by individuals, in a context of assured dignity, access to needed supports for palliative care or for continuing to live in the community, information about alternative courses of action where available, and informed consent.

We must also make sure that protocols are in place to address the situations where a person's dignity has been systemically harmed because of devaluation on the basis of disability, social exclusion, abuse and lack of access to needed supports. It is when people lack needed support and a sense of dignity in relation to others that they can come to feel like a burden, experience social isolation and thus lose a sense of autonomy over their own lives. In this context, choice for assisted suicide may not always be entirely self-determined. The demographic overview provided raises extremely serious concerns about introducing a system for physician-assisted death in a context of the rapidly growing population of Canadians with a disability and their systematic disadvantage, devaluation and victimization.

In this context, we must design the system to ensure that as people gain access to physician-assisted suicide and voluntary euthanasia, on the basis of protecting their autonomy and dignity, this does not undermine or diminish equal community respect and solidarity with others who continue to live and seek to thrive with similar medical conditions or disability.

In order to ensure that Canadians can find some common ground on which to build a system, we urge that key actors and stakeholders keep in view the interdependent values of autonomy, dignity *and* inclusion. Collectively abiding by these values and associated principles and guidelines will help build necessary bridges and address legitimate concerns. Guided, as well, by Canada's obligations under the *UN Convention on the Rights of Persons with Disabilities* we fundamentally believe this will require a system for regulating access to physician-assisted suicide and voluntary euthanasia that has as its main pillars: vulnerability assessment; advance independent review and authorization; monitoring and public reporting to Parliament and provincial/territorial legislatures; and a coordinated engagement and investment strategy. Without these pillars firmly in place, the Supreme Court of Canada's requirement that the system must protect persons who may be vulnerable to inducement to commit suicide cannot be met; nor can Canada's obligations under the *UN Convention on the Rights of Persons with Disabilities*.

Developing and implementing a system for regulating physician-assisted suicide and voluntary euthanasia must be a coordinated legislative, policy and program development priority. Both



levels of government have a duty to legislate, invest and regulate. We must avoid at all costs uneven and risky developments across the country. For this purpose, and in addition to embedding the requirements of the system in the *Criminal Code*, a joint federal-provincial/territorial government and community table must be established. It should be mandated to develop a shared framework for: regulating access to physician-assisted suicide and voluntary euthanasia; investing in palliative care and disability supports; guiding and monitoring implementation; and recommending and negotiating changes to the system as needed.

The disability community in Canada has been profoundly affected by the *Carter* judgment because of the risk we believe it poses to advancing inclusion, equality and human rights for Canadians with disabilities. We hope the proposals presented here are taken in the spirit and with the purpose for which they were developed: that of finding common ground in the design of a system for physician-assisted suicide and voluntary euthanasia in Canada that protects real choice and safeguards inclusion. We urge that foresight, caution, compassion and core values guide us all in the exercise ahead so that the system will contribute to, rather than undermine, autonomy, dignity and inclusion for all Canadians throughout their lifetimes.

## Endnotes

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- <sup>1</sup> *Carter v. Canada (Attorney General)*, 2015 SCC 5.
- <sup>2</sup> *Carter v. Canada (Attorney General)*, 2015 SCC 5 at para 125.
- <sup>3</sup> The Royal Society of Canada Expert Panel (November 2011). *End-of-Life Decision Making*. Ottawa: Royal Society of Canada, at p. 7.
- <sup>4</sup> Statistics Canada, Social and Aboriginal Affairs Division (2013). Disability in Canada: Initial findings from the Canadian Survey on Disability: Fact Sheet. Ottawa: Statistics Canada.
- <sup>5</sup> Douglas Durst (2006). Urban First Nations People with Disabilities Speak Out. *Journal of Aboriginal Health* (September 2006).
- <sup>6</sup> For a comparison of 2001 and 2006 disability rates in these population groups, see Statistics Canada, *Participation and Activity Limitation Survey: Analytical Report* (Ottawa: Statistics Canada, 2007), online: <http://www.statcan.gc.ca/pub/89-628-x/89-628-x2007002-eng.htm> (last accessed: 24 September 2014).
- <sup>7</sup> Rubab Arim (2015). *A profile of persons with disabilities among Canadians aged 15 years or older, 2012*. Ottawa: Statistics Canada.
- <sup>8</sup> The Honourable Sharon Carstairs (2010). *Raising the Bar: A Roadmap for the Future of Palliative Care in Canada*. Ottawa: Senate of Canada, at p. 24.
- <sup>9</sup> Quality End-of-Life Care Coalition of Canada (2010). *Blueprint for Action: 2010 to 2020*. Ottawa: Author, at p. 1.
- <sup>10</sup> P. Smetanin, D. Stiff, C. Briante, C.E. Adair, S. Ahmad and M. Khan (2011). *The Life and Economic Impact of Major Mental Illnesses in Canada: 2011 to 2041*. Toronto: RiskAnalytica, on behalf of the Mental Health Commission of Canada.
- <sup>11</sup> See Samuel Perrault (2009). *Criminal victimization and health: A profile of victimization among persons with activity limitations and other health problems*. Ottawa: Statistics Canada.
- <sup>12</sup> Christine Bizier, Carley Marshall and Gail Fawcett (2014). *Mental health-related disabilities among Canadians aged 15 years and older, 2012*. Ottawa: Statistics Canada.
- <sup>13</sup> Cameron Crawford (2013). Looking Into Poverty: Income Sources of Poor People with Disabilities in Canada. Toronto: IRIS - Institute for Research and Development on Inclusion and Society, 2013. Online: <http://www.ccdonline.ca/en/socialpolicy/poverty-citizenship/demographic-profile/income-sources-of-poor-people-with-disabilities>; Crawford, C. (2013 version). *Disabling Poverty & Enabling Citizenship: Understanding the Poverty and Exclusion of Canadians with Disabilities*. Winnipeg: Council of Canadians with Disabilities. Online: <http://www.ccdonline.ca/en/socialpolicy/poverty-citizenship/demographic-profile/understanding-poverty-exclusion>.
- <sup>14</sup> For statistics referenced in this section, see Samuel Perrault (2009). *Criminal victimization and health: A profile of victimization among persons with activity limitations and other health problems*. Ottawa: Statistics Canada.
- <sup>15</sup> National Clearing House on Family Violence (2004). *Violence Against Women with Disabilities*. Ottawa: Minister of Public Works and Government Services Canada.
- <sup>16</sup> Larry Chartrand and Celeste McKay (2006). *A Review of Research on Criminal Victimization and First Nations, Métis and Inuit Peoples 1990-2001*. (Ottawa: Department of Justice Canada).
- <sup>17</sup> See P. Heslop et al (2014) The Confidential Inquiry into premature deaths of people with intellectual disabilities in the UK: a population-based study. *The Lancet*; 383: 9920, 889–895; and Stacey Atkinson, Joanne Lay, Su McAnelly, Malcolm Richardson (eds.) (2015), *Intellectual Disability in Health and Social Care*. New York: Routledge.
- <sup>18</sup> P. Smetanin, P. Kobak, C. Briante, D. Stiff, G. Sherman, G. and S. Ahmad, *Rising Tide: The Impact of Dementia in Canada 2008 to 2038*. Toronto: Alzheimer Society Canada.
- <sup>19</sup> Canadian Institute for Health Information (2010). *Depression among Seniors in Residential Care: An Analysis in Brief*. Ottawa: Author.
- <sup>20</sup> See, for example, E. Podnieks (2008), Elder abuse: the Canadian experience. *Journal of Elder Abuse and Neglect*, 20(2):126-50; Charmaine Spencer (1998). *Diminishing Returns: An Examination of Financial Abuse of Older Adults in British Columbia*. Vancouver: Gerontology Research Centre, Simon Fraser University.
- <sup>21</sup> *Carter v. Canada (Attorney General)*, 2015 SCC 5 at para 2.
- <sup>22</sup> *Carter v. Canada (Attorney General)*, 2015 SCC 5 at para 67.

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- <sup>23</sup> *Carter v. Canada (Attorney General)*, 2015 SCC 5 at para 67.
- <sup>24</sup> Christopher McCrudden (2008). Human Dignity and Judicial Interpretation of Human Rights. *The European Journal of International Law* Vol. 19 no. 4.
- <sup>25</sup> *Law v. Canada (Minister of Employment and Immigration)*, [1999] 1 S.C.R. 497 at para. 53.
- <sup>26</sup> *R. v. Labaye*, 2005 SCC 80 at para. 46.
- <sup>27</sup> *Carter v. Canada (Attorney General)*, 2015 SCC 5 at para 65.
- <sup>28</sup> *Eldridge v. British Columbia (Attorney General)*, [1997] 3 S.C.R. 624 at para. 59.
- <sup>29</sup> A seminal essay by Canadian philosopher, Charles Taylor, launched a rich literature on how social recognition of one's group characteristics shape one's experience of dignity. See Charles Taylor (1994). *The Politics of Recognition. Multiculturalism: Examining the Politics of Recognition*. Ed. Amy Gutmann. Princeton: Princeton University Press, pp. 25-73. In a series of more recent studies, Axel Honneth has examined the inter-relationship between valued recognition of one's group status, and the experience of dignity. See, for example, Axel Honneth (2012). *The I in We: Studies in the Theory of Recognition*. Cambridge: Polity Press.
- <sup>30</sup> Canadian Hospice Palliative Care Association (2006), CHPCA Issues Paper on Euthanasia, Physician-Assisted Suicide and Quality End-of-Life Care. Ottawa: Author.
- <sup>31</sup> Tom Shakespeare (2006). *Disability Rights and Wrongs*. Abingdon: Routledge, p. 129.
- <sup>32</sup> The Royal Society of Canada Expert Panel (November 2011). *End-of-Life Decision Making*. Ottawa: Royal Society of Canada, p. 99.
- <sup>33</sup> *Québec (Commission des droits de la personne & des droits de la jeunesse) v. Montréal (City)*, 2000 SCC 27, [2000] 1 S.C.R. 665, [2000] S.C.J. No. 24 at para. 79 [Mercier].
- <sup>34</sup> *Carter v. Canada (Attorney General)*, 2015 SCC 5 at para 77.
- <sup>35</sup> See, for example, Peadar Kirby (2006), *Vulnerability and Violence: The Impact of Globalisation*. London: Pluto Press.
- <sup>36</sup> Jo-Ann Pickel (2007). Supreme Court of Canada Grapples with the Social Construction of Disability: Council of Canadians with Disabilities v. Via Rail. Online: <http://www.cavalluzzo.com/resources/publications/details/supreme-court-of-canada-grapples-with-the-social-construction-of-disability-council-of-canadians-with-disabilities-v.-via-rail>.
- <sup>37</sup> For a discussion of these themes in the Supreme Court of Canada's jurisprudence see, for example, Yvonne Peters and Debra Parkes (2014). Making Poverty a Human Rights issue for People with Disabilities. Online: <http://ccdonline.ca/en/socialpolicy/poverty-citizenship/legal-protections/making-poverty-a-human-rights-issue-for-people-with-disabilities>; and Judith Mosoff (2009). Lost In Translation? The Disability Perspective In Honda V. Keays and Hydro-Québec V. Syndicat. *McGill Journal of Law and Health*, Vol. 3.
- <sup>38</sup> *Moore v. British Columbia (Education)*, 2012 SCC 61, at para. 36.
- <sup>39</sup> Law Commission of Ontario (2012). *A Framework for the Law as it Affects Persons with Disabilities*. Toronto: Author, p. 82.
- <sup>40</sup> Kerri Joffe (ARCH Disability Law Centre), 2010. Enforcing the Rights of Persons with Disabilities in Ontario's Development Services System. Toronto: Law Commission of Ontario. Online: <http://www.lco-cdo.org/en/disabilities-call-for-papers> [Joffe], p. 31.
- <sup>41</sup> Martha Albertson Fineman (2010-2011), The Vulnerable Subject and the Responsive State, *60 Emory L.J.* 251, pp. 255-256.
- <sup>42</sup> See Michael Bach and Lana Kerzner (2010), A New Paradigm for Protecting Autonomy and the Right to Self-Determination. Toronto: Law Commission of Ontario. Online: <http://www.lco-cdo.org/disabilities/bach-kerzner.pdf>, p. 84. This formulation is similar to the definition of capacity in the Northwest Territories' *Guardianship and Trusteeship Act*, S.N.W.T., 1994, c.29, s.12(1).
- <sup>43</sup> John Keown (2014), A Right to Voluntary Euthanasia? Confusion in Canada in Carter. *Notre Dame Journal of Law, Ethics & Public Policy*, 28:1, at pp. 4-17.
- <sup>44</sup> *Carter v. Canada (Att'y General)*, [2012] B.C.S.C. 886 (Can. B.C.). This judgment was largely drawn upon and supported by the Supreme Court of Canada in its ruling in the Carter appeal.
- <sup>45</sup> *Health Care Consent Act*, 1996, S.O. 1996, c. 2 s. 11(3)5.
- <sup>46</sup> See, for example, discussion of 'undue influence' and 'suspicious circumstances' in British Columbia Law Institute (2013), *Report on Common-Law Tests of Capacity*. Vancouver: Author.

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<sup>47</sup> See Michael Bach and Lana Kerzner (2010), *A New Paradigm for Protecting Autonomy and the Right to Self-Determination*. Toronto: Law Commission of Ontario. Online: <http://www.lco-cdo.org/disabilities/bach-kerzner.pdf>.

<sup>48</sup> U.N. Human Rights Committee, *Consideration of Reports Submitted by States Parties Under Article 40 of the Covenant*, para. 7, U.N. DOC. CCPR/C/NLD/CO/4 (Aug. 25, 2009). See also U.N. Human Rights Committee, *Concluding Observations of the Human Rights Committee: Netherlands*, para. 5–6, U.N. DOC. CCPR/CO/72/NET (Aug. 27, 2001).

<sup>49</sup> For an overview of this research and a critique of the evidence relied upon in *Carter* to determine adequacy of safeguards, see John Keown (2014), *A Right to Voluntary Euthanasia? Confusion in Canada in Carter*. *Notre Dame Journal of Law, Ethics & Public Policy*, Vol. 28, Issue 1, pp. 1-46.

<sup>50</sup> J. Pereira (2011). *Legalizing euthanasia or assisted suicide: the illusion of safeguards and controls*. *Current Oncology*, 18(2); Mary Shariff (2012), *Assisted death and the slippery slope—finding clarity amid advocacy, convergence and complexity*. *Current Oncology*, 19(3).

<sup>51</sup> Mary Shariff (2012), *Assisted death and the slippery slope—finding clarity amid advocacy, convergence and complexity*. *Current Oncology*, 19:3.

<sup>52</sup> The Honourable Sharon Carstairs (2010). *Raising the Bar: A Roadmap for the Future of Palliative Care in Canada*. Ottawa: Senate of Canada, at p. 24.

<sup>53</sup> Quality End-of-Life Care Coalition of Canada (2010). *Blueprint for Action: 2010 to 2020*. Ottawa: Author, at p. 1.

<sup>54</sup> Quality End-of-Life Care Coalition of Canada (2010). *Blueprint for Action: 2010 to 2020*. Ottawa: Author, at p. 1.

<sup>55</sup> Rubab Arim (2015). *A profile of persons with disabilities among Canadians aged 15 years or older, 2012*. Ottawa: Statistics Canada.

<sup>56</sup> David Baker and Gilbert Sharpe (2015), *Draft Federal Legislation to Amend the Criminal Code to be Consistent with Carter v. Canada (Attorney General) 2015 SCC 5*. Toronto: *bakerlaw*.

<sup>57</sup> The Royal Society of Canada Expert Panel (November 2011). *End-of-Life Decision Making*. Ottawa: Royal Society of Canada, p. 97.