

**Impacts of the Medical Assistance in Dying (MAiD) Regime  
on People with Disabilities: Towards a research programme**

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**June 2021**

## Introduction

Advisors to the Vulnerable Persons Standard (VPS)<sup>1</sup> have been considering questions raised by disability communities, health and legal professionals, ethicists, and policy makers about the impacts of Canada's medical assistance in dying (MAiD) regime – its laws, policies, and practices. Our concerns focus on the impact of the MAiD regime on the equality rights of people with disabilities. These concerns are heightened with Bill C-7, the recent legislation expanding access to MAiD from its original restriction under Bill C-14 to people who are suffering at the end of life, to now include people with disabilities even if they are not dying. The Bill also provides that by March 2023 access will be further expanded to authorize MAiD based on mental illness as a sole underlying condition.

In this context, some of the advisors to the VPS met to consider parameters for a research programme, as described below. The overall aim is to generate and mobilize knowledge from an equality rights perspective to inform future statutory reviews, legislative and regulatory development, jurisprudence, and policy guidance related to the MAiD regime. This rights-based approach is grounded both in the *Charter* and the *UN Convention on the Rights of Persons with Disabilities*. It also reflects the central animating concern of the Vulnerable Persons Standard, i.e., that access to physician-assisted death must be balanced by our ethical and constitutional duties to protect persons who are vulnerable to inducement or coercion because of unmet social needs.

Addressing these questions will require a series of studies, which VPS Advisors are beginning to scope out and for which they are seeking research and funding partnerships. We also expect that these objectives and questions could provide a framework for synthesizing findings from research already conducted and currently underway.

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<sup>1</sup> The 'Vulnerable Persons Standard' is a human rights-informed and evidence-based set of requirements to guide development and monitoring of laws, policies, and practices for medical assistance in dying consistent with the Canadian *Charter of Rights and Freedoms* and the United Nations *Convention on the Rights of Persons with Disabilities*. It was developed by over 50 expert advisors in disability, law, ethics, and health care, and endorsed by numerous disability, civil society and professional associations. See [www.vps-npv.ca](http://www.vps-npv.ca).

VPS advisors propose that six main concerns motivate and could organize a research programme from an equality and disability human rights perspective:

1. Widening scope of the regime beyond end of life
2. Lived realities and risks of inducement
3. Extent to which informed consent and exploration of alternative courses of action guide decision making
4. Further institutionalizing ableism and discriminatory impact, undermining foundations of inclusion, dignity, and equality
5. Impact on ethical responsibilities, conscience rights and obligations of medical professionals
6. Inadequate data collection, monitoring and reporting.

## **1. Widening scope of the regime beyond end of life:**

### **Background**

We are witnessing a trend in Canada seen in other jurisdictions where legislators begin by authorizing provisions that restrict access to assisted suicide for people at the end of life, and then accede over time to pressures to expand access. As this happens, assumptions about the equal value of all lives, about the necessity of informed consent at the moment of euthanasia, and about the ethics of health care all begin to shift. The precise nature, extent and implications of these shifts are neither widely recognized nor fully understood.

The Supreme Court of Canada in its *Carter* decision found that the persistent and seemingly inexorable drift toward more and more permissive regimes in jurisdictions that did not legislate a bright line limiting death-hastening practices to end-of-life conditions, were “the product of a very different medico-legal culture.” With the passage of Bill C-7, expansion beyond end-of-life in Canada signals that the “medico-legal culture” has already shifted in a short five years.

Mapping and understanding the changing nature of laws, policies and practices of MAiD, and the underlying shifts in medical and legal culture both justifying and being shaped by these regime changes, is critical to tracking the implications for equality rights and inclusion in Canada.

## Research Objective

To understand the evolving nature of the MAiD regime in Canada – its evolving laws, policies, and practices – in relation to legislative and political commitments, the value set underlying the regime and comparable regimes internationally. Further, to track how these evolving laws, policies and practices affect, directly and indirectly, the lives of Canadians across the full spectrum of demographic, socioeconomic, racial, and cultural diversity.

## Research Questions

- 1.1. What are the parameters of the MAiD regime at both federal and provincial/territorial levels, and as instituted through legislation, regulatory development, jurisprudence, policy guidance by health care regulators, decisions of relevant administrative tribunals, and practice guidelines and training resources developed and adopted by/for medical professionals?
- 1.2. How have these parameters evolved over time, through what decision-making processes, and what are the key drivers and factors influencing this evolution?
- 1.3. What, if any, are the significant variations or outliers that depart from the trends and parameters identified in 1.1 and 1.2?
- 1.4. With the widening scope of the regime, the terms and discourse of eligibility have shifted from providing autonomy at the end of life, to enabling access to MAiD for people who are suffering, if they have a disability.
  - How is the emergent discourse of suffering, as justification for MAiD, shaping our understanding of what constitutes pain and suffering, their dimensions, their root causes, and appropriate ethical and biomedical responses?
  - What are the ethical, legal, and political implications of this shifting narrative of suffering in Canada in a context where mental illness, dementia and pain-related disabilities are among the fastest growing types of disability?
- 1.5. How is the MAiD regime evolving considering legislative and policy objectives, political commitments, and value assumptions, and how does this evolution compare to other regimes internationally?
- 1.6. What are the ethical and legal arguments for restricting access to MAiD to people who are suffering at the end of life?
  - Would an application of the proportionality doctrine, in a manner that accounts for harms that will come with expanding access beyond end of

life, justify re-instituting this restriction and what kinds of evidence would be required for this purpose?

## **2. Lived realities and risks of inducement:**

### **Background**

With access extended under Bill C-7 to people with disabilities who are not at the end of life, there is growing concern that people may be induced to request MAiD because of suffering associated with disproportionately high rates among this group of poverty, isolation, unmet disability support needs and the absence of other social determinants of health. Similarly, the debilitating impacts on health and well-being that result from systemic ableism and intersections with other forms of structural exclusion (e.g., racism, colonialism, sexism) require careful attention when state agents are authorized to perform life-ending interventions. Moreover, there are growing concerns about the threats to social cohesion including through the devaluation of people with disabilities including by online hate and malicious disinformation.

Inducement to request MAiD to commit suicide is a very real concern in this context. How will the regime address the ongoing, and now much expanded, risk of inducement under the provisions of Bill C-7? How will it counter the social and online harms and viral disinformation and misinformation about the realities and value of living with disability, and about the presumed autonomy and dignity that MAiD has come to represent in some discourses? Does the distinction on which the MAiD regime rests – that you can identify those being ‘induced’ because it is possible to draw a bright line between well-reasoned wishes to die and suicidality – hold up to critical scrutiny in a context of widespread systemic ableism, racism and ageism, rapid dissemination of narrative distortions and memes and a much-expanded regime?

### **Research Objective**

To gain a deeper understanding of factors that may be inducing people to request MAiD, or as the Supreme Court of Canada put it in the *Carter* decision, “to commit suicide at a time of weakness.”

### **Research Questions**

- 2.1. What constitutes inducement, a non-voluntary request and external pressure in requests for and consent to MAiD?
- 2.2. To what extent are people being induced to request MAiD by conditions and circumstances other than suffering from their medical symptoms (i.e., for reasons related to the social determinants of health, including poverty, homelessness or precarious housing, isolation, and inaccessible medical services, palliative care and disability supports -e.g., attendant services, aids, and devices, etc.)?
- 2.3. Some Canadians with disabilities have been declaring publicly that they will be, or have been, seeking out access to MAiD. How are these Canadians situated with respect to the social determinants of health? Understanding that suffering and circumstances are multifactorial, what can be gleaned about what is motivating their requests? What role does “external pressure” as identified in the *Criminal Code* play in making these requests? Were identity characteristics a factor (i.e., do people with certain types of disabilities or racialized people with disabilities or other groups report more instances of being induced)?
- 2.4. How does the broader social context, including the lack of substantive equality across so many domains in society, contribute to persons with disabilities being vulnerable to using an expanded MAiD regime to commit suicide?
- 2.5. In practice, how are medical professionals differentiating MAiD requests from suicidal ideation and what tools and lenses are being applied for this purpose?
- 2.6. What procedures and tools are being applied to ensure that the eligibility requirement of a patient’s suffering *because of a medical condition* is met in all cases? Given the complex causation of human suffering, how are these determinations parsed and recorded? How is suffering caused by a medical condition differentiated from suffering caused by a social condition, such as poverty, homelessness, food insecurity etc.?
- 2.7. Given that certain complaints such as “unable to communicate” or “loss of autonomy” might be seen through an ableist lens as resulting from disability, rather than from “lack of access to communication technologies” or “lack of choice or control about personal supports”, how are MAiD practitioners and regulators

working to ensure that practices of medical assistance in dying do not proceed from and entrench social disadvantage and harm?

- 2.8. To what extent is the distinction on which the MAiD regime operates, between a ‘well-reasoned wish to die’ and ‘suicidality,’ supported by substantive research findings and if it is, in what contexts? In Canada’s permissive regime for MAiD, how do systemic ableism, racism, ageism, and their manifestations in popular and online culture contribute to inducing people to request MAiD, and how are those risks exacerbated in a much-expanded regime?

### **3. Extent to which informed consent and exploration of alternative courses of action guide decision making:**

#### **Background**

There are serious concerns about the assessment processes, range of alternatives explored and informed consent protocols for MAiD, in a context where rates of access are increasing at an alarming rate year-over-year and in some provinces more than others. These concerns are sharpened with individual cases of undue pressure, deplorable conditions of neglect and highly questionable medical judgements <sup>2</sup>already well documented, the frequency of which will likely increase with much wider eligibility under Bill C-7. The inclusion of mental illness as a sole underlying condition by March 2023, and intensifying pressures to expand access even further through advance directives for those who are unable to provide informed consent at the time of administering MAiD, point to a concerning trend on the horizon.

#### **Research Objective**

To examine the extent to which standards of informed consent are being met in health care decision making related to MAiD and the ways in which disputes about capacity to consent are being managed, and to gain insight into implications of authorizing advance directives for MAiD.

#### **Research Questions**

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<sup>2</sup> For an overview of a number of cases of concern suggesting inducement to request and consent to MAiD, see Advisors to the Vulnerable Persons Standard, “Failing People with Disabilities who Experience Systemic Suffering: Gaps in the Monitoring System for Medical Assistance in Dying” (October, 2020), online:

<https://static1.squarespace.com/static/56bb84cb01dbae77f988b71a/t/5f90666476d4f07d2c0233dc/1603298916667/MAiD+Monitoring+-+Failing+People+with+Disabilities+-+Final.pdf>.

- 3.1. How are standards of informed consent being applied and evolving in MAiD decision making, including requirements to ensure patients understand the nature of the intervention and appreciate its consequences; voluntariness and absence of external pressure; exploration and consideration of alternative courses of action; and capacity to consent and reasonable accommodations for that purpose.
- 3.2. What policies and practices are being adopted to guide exploration of alternative courses of action as part of the decision-making process, and what is the nature and extent of this exploration (for both ‘tracks’ of access to MAiD – those requesting at the end of life, and those who are not at the end of life)?
- 3.3. What are the varying alternative courses of action being considered at this stage of in the consent procedure? What are the range of teams and methods employed for this purpose? To what extent are evidence-based alternatives to pharmaceutical treatments figuring in these explorations? To what extent are community-based treatments figuring as alternative courses of action, and to what extent are they ruled out because of prohibitively long wait lists?
- 3.4. How is “external pressure” defined for the purposes of MAiD assessment and does this definition include pressure arising from one’s life circumstances, rather than direct interpersonal exchanges?
- 3.5. What procedures and tools are being applied to ensure that the request and decision are not the result of “external pressure,” as required under the *Criminal Code*?
- 3.6. How are concerns about capacity to consent being managed, including steps taken to ensure that disability-related accommodations are provided, and how are disputes about capacity being addressed?
- 3.7. What can we learn from experience in other jurisdictions about managing the consent process for persons who access MAiD, in a manner consistent with ensuring the decision reflects true intentions, adequate understanding and appreciation, and voluntariness?

**4. Further institutionalizing ableism and discriminatory impact, undermining foundations of inclusion, dignity, and equality:**



## Background

Given the pervasiveness of ableism in Canadian society, there are significant concerns about the further corrosive impact of wider eligibility on the equal status, dignity, and recognition before and under the law of the growing proportion of people living with disability. Bill C-7 is a radical departure from the original legislation insofar as it removes what was a universal criterion – that a person had to be at the end of life to be eligible. In doing so, the new legislation singles out a *Charter*-protected group, intimately familiar with discrimination in everyday life, for whom MAiD will now be exclusively available in addition to those at the end of life – people with disabilities.

Singling out disabled persons as a new category for whom a distinct rationale permits medical assistance in dying risks embedding and institutionalizing ableist perspectives ever more deeply into cultures of law, medicine, and society generally. We need to better understand how this new construction of death as a benefit rather than a harm for people with disabilities will affect how disabled persons are perceived both in healthcare regimes and more broadly, and how disabled persons themselves will feel the effects of this change in their social and legal status. Understanding the impact of Bill C-7 on personal and societal perceptions of disability is essential to evaluate its effectiveness in securing the Bill's preambular commitments to equal protection and benefit of the law without discrimination, and to assess the harms that failure in this regard would permit.

## Research Objective

To assess the extent to which expanding access to MAiD exclusively on the *Charter*-protected ground of disability may entrench and exacerbate the structural ableism already evident in our systems of health care and justice, and in Canadian society at large. Further, to assess any adverse effects with respect to the social conditions of inclusion and equal respect for people with disabilities.

## Research Questions

- 4.1. What are the ways in which people with disabilities are made vulnerable in a regime that permits the termination of life under conditions of disability, and to what extent does an expanding MAiD regime further entrench the systemic ableism that underlies that vulnerability?
- 4.2. How is the expanding MAiD regime resulting in culture change in Canadian political, health care and legal discourses as it positions certain bodies, minds, and lives as justifiably terminated, and to

what extent do these discourses harm the equality rights of people with disabilities?

- 4.3. What messages does the expanded MAiD regime send to people with disabilities about their equal recognition in Canadian society, how are these messages internalized, and what lasting impact do they have?
- 4.4. What culture changes are resulting from the evolving MAiD regime in terms of perceptions, motivations, attitudes, and behaviors? How do these culture changes play out in Canadian institutions (including health and justice systems), and within the networks of people with disabilities (friends, families, and support staff)? How do these compare with international developments?
- 4.5. How are media accounts and portrayals of disability shifting across in the context of an expanding MAiD regime? How are narrative accounts of disability, and memes and metaphors that draw from disability, shifting across the spectrum of cultural production (film, literature, and other artistic forms)?
- 4.6. Since the adoption of the MAiD regime, the federal government committed to a national framework for palliative care, to achieving and inclusive and accessible Canada by 2040 with the adoption of the *Accessible Canada Act*, a national housing strategy with targets to address housing needs of people with disabilities, a national disability action plan with a new 'Canada Disability Benefit,' and various other measures related to supports for students with disabilities, assistive technology investment, and expanded employment-related supports:
  - What commitments have federal and provincial/territorial governments made to disability supports and services, poverty reduction, palliative care, and accessibility, in relation to or in the context of justifying MAiD?
  - To what extent have governments delivered on these commitments and with what level of fiscal effort; and what is the impact on addressing existing and growing gaps?
  - What can we learn from international experience about the extent to which adoption of MAiD-related regimes are associated with parallel investments in disability supports, accessibility and inclusion in these respective regimes?
- 4.7. To what extent does the cost-savings data reported in the wake of adopting and expanding the MAiD regime influence political, health care and legal discourses about the societal benefits of a MAiD

regime and affect the social positioning of people who may be eligible to use the regime to terminate their lives?

## **5. Impact on ethical responsibilities, conscience rights and obligations of medical professionals:**

### **Background**

With Bill C-7's much expanded criteria for access to MAiD, there are pressing ethical and legal questions about protecting the conscience rights of medical professionals. While these concerns were raised in the context of the parameters defined by Bill C-14, they grow more urgent with the vastly widened access criteria.

### **Research Objective**

To better understand the threat that Bill C-7 introduces to the set of ethical principles considered foundational to health care, which go beyond respect for autonomy to include non-maleficence, beneficence, and justice.

### **Research Questions**

- 5.1. What does the protection of conscience rights require in the context of an expanded regime for medical assistance in dying? What are the impacts upon health professionals if these requirements are not fully met? What are the impacts upon persons who are vulnerable to inducement if these requirements are not fully met?
- 5.2. To what extent are foundational biomedical ethical principles undermined by Bill C-7? How have regimes that permit medical assistance in dying for persons who are not at the end-of-life reconciled these apparent ethical conflicts?
- 5.3. Should medical professionals who oppose the termination of the lives of people who are not dying, particularly based on their disability, be held liable for refusing to participate in a regime designed for this purpose? What are the potential impacts if they are held liable, both on practitioners and on patients?
- 5.4. How can a *Charter* and CRPD-informed analysis contribute to our understanding of legal obligations of medical professionals in the context of an expanded MAiD regime?

## **6. Inadequate data collection, monitoring and reporting:**

### **Background**

Regulations for data collection, monitoring and reporting have been a subject of considerable debate, both in the aftermath of Bill C-14's coming into force, and in the legislative debates leading up to the adoption of Bill C-7. Many advocated for more extensive data gathering than the federal government ultimately adopted in its regulations to Bill C-14.<sup>3</sup>

The gaps in knowledge are becoming more evident all the time. A solid base of data is needed about who is requesting and accessing MAiD, stated reasons for the requests, and socio-economic factors and determinants of health which may be motivating the requests. Without that, and an 'open data' approach to accessing and analyzing the database, there will be no full disclosure leaving Canadians unable to adequately assess whether safeguards are working, to detect any discriminatory trends, and to understand any adverse impacts affecting people who are vulnerable to being induced to commit suicide by MAiD.

### **Research Objective**

To identify the extent to which data collection, access to data, monitoring and reporting under the MAiD regime provide for full transparency about who is accessing MAiD, why, and the extent of adherence to legislated safeguards and standards for informed consent.

### **Research Questions**

- 6.1. To what extent does the existing data about MAiD access and usage reveal discriminatory impact of the MAiD regime on people with disabilities broadly, and people with intersecting identities that include disability in particular?
- 6.2. What are the key gaps in the current state data collection, analysis, and reporting system to ensure transparency about who is requesting and accessing MAiD, their stated reasons, and socio-

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<sup>3</sup> See Advisors to the Vulnerable Persons Standard, "Towards a More Robust Monitoring Regime for Medical Assistance in Dying" (February, 2018), online: <https://static1.squarespace.com/static/56bb84cb01dbae77f988b71a/t/5a845f84ec212da3285ab163/1518624645431/VPS+Submission+on+Federal+MAiD+Monitoring+Regulations+-+FINAL.pdf>.

economic factors and social determinants of health which may be motivating the requests?

- 6.3. What additional gaps are anticipated given Bill C-7, and how should these be addressed?
- 6.4. To what extent are current regulations and arrangements for accessing data on the MAiD system based on an 'open data' approach, and enabling and encouraging broad access for research purposes, and what steps should be taken to improve access for this purpose?

## **Next Steps in Building a Research Programme**

VPS advisors have suggested a few next steps to launch this programme:

- Consolidate a research programme agenda – based on inputs and feedback on this draft.
- Identify research leads for the thematic areas, including academic and institutional leads.
- Develop research collaboratives/networks for each of the thematic areas to tap expertise and resources, and to develop a research plan in each area.
- Tap those networks to identify existing resources – financial and in-kind (e.g., summer students, graduate assistants, etc.) to initiate work on the respective research plans (e.g., literature scans, etc.).
- Explore funding opportunities for larger scale, multi-year funding to undertake needed research.

## **Managing the Collaboration**

While we are at very preliminary stages, a few key steps are needed:

- Identifying leads and furthering the discussion and development of a plan.
- Recruiting additional researchers to deepen and broaden our capacity.
- Creating a network, and arranging network support, for this purpose.
- Creating a platform for sharing information and collaborating
- Finding ways to consolidate, synthesize and disseminate findings, 'mobilizing the knowledge,' for use by those seeking research findings and evidence for:
  - Inputs to Parliamentary review of the legislation
  - Consultations on regulatory development under Bill C-7
  - Litigation efforts challenging the expansion of the MAiD regime under Bill C-7.