

A Call for Safeguards

Submission by ARCH Disability Law Centre

to the Standing Committee on Justice and Human Rights

regarding

Bill C – 14 An Act to amend the Criminal Code and to make related amendments to other Acts (Medical Assistance in Dying)

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Introduction

In *Carter v. Canada*, the Supreme Court of Canada tasked this Government with the creation of a framework to govern access to physician-assisted death while also protecting persons who are vulnerable to inducement or coercion. The Court concluded, “a properly administered regulatory regime is capable of protecting the vulnerable from abuse and error.”¹ It further found that “adults who may be vulnerable to committing suicide in a time of weakness” should be protected.² While Bill C-14 provides the minimum standards, additional safeguards are necessary to address the concerns of Canada’s diverse disability communities, including the need for a “carefully designed” and balanced system.³

About ARCH

ARCH Disability Law Centre (“ARCH”) is a specialty legal clinic dedicated to advancing the equality rights of persons with disabilities. ARCH is primarily funded by Legal Aid Ontario and provides legal services to help Ontarians with disabilities live with dignity and participate fully in our communities. Through our Provincial mandate, we work with Ontarians with disabilities and disability communities providing direct legal representation in systemic litigation, we conduct law reform activities, and policy and community development work. We also provide public legal education to persons with disabilities and continuing legal education to the legal community. ARCH maintains a website at www.archdisabilitylaw.ca. Our submissions are driven by our work with Ontarians with disabilities and their experiences of coercion and the impact of ableist stereotypes, including about their prospects for recovery and quality of life.

ARCH has endorsed the Vulnerable Persons Standard and two members of its Staff are Advisors to the Standard (<http://www.vps-npv.ca/readthestandard/>).⁴ The five-part Standard developed a system that would support adults who may be motivated by a range of circumstances separate from their end-of-life conditions. Those circumstances include barriers to palliative care, presumptions about their quality of life and prospect for recovery, and barriers to disability supports and services.

The following submissions are not comprehensive. Instead, ARCH relies on the work of the Vulnerable Persons Secretariat and the submissions made by its Advisers.⁵ ARCH commends the Government for adopting a minimum standard of safeguards to address the vulnerability of persons with disabilities who seek physician-assisted death. ARCH

¹ *Carter v. Canada (Attorney General)*, [2015] 1 SCR 331 at para 3.

² *Carter*, *supra* at 29.

³ *Carter*, *supra* at 117.

⁴ Robert Lattanzio, Executive Director, ARCH Disability Law Centre; C. Tess Sheldon, Staff Lawyer, ARCH Disability Law Centre.

⁵ Vulnerable Persons Standard online: www.vps-npv.ca/materials-related-to-bill-c14.

strongly urges the Committee to strengthen the minimum safeguards set out in Bill C-14. To do that, ARCH makes two specific recommendations.

Recommendation 1: An Explicit Right to Information about Alternatives

ARCH's work is dedicated to the promotion of the inclusion of persons with disabilities in decisions that affect them. Bill C-14 must recognize the explicit right for persons to be informed of the full range of available supports that could reduce their sources of vulnerability and related barriers. Vulnerability can have many sources, including ableist presumptions about a person's quality of life. The provision of information about palliative care options must be made explicit in the body of the amendments, and not only in the *Preamble*.

Attention must be paid to the upstream factors that influence the wellbeing of persons with disabilities, including the social determinants of health such as poverty, housing and disability supports and services. ARCH provides legal services to Ontarians with disabilities whose legal issues are compounded by poverty, who also face barriers to accessing necessary and appropriate housing, community supports, health care and palliative care.

ARCH acknowledges Canada's commitment to "support the improvement of a full range of options for end-of-life care", as set out in the *Preamble*. To fulfil this commitment, s. 241.2(3) must codify a person's right to information about those "full range of options". Persons with disabilities who seek a physician-assisted death must be informed of and understand all alternatives. Bill C-14 must include additional safeguards to support them to pursue any acceptable alternatives including palliative care.

Access to this information is crucial to ensuring opportunities for persons with disabilities to make informed end-of-life decisions. Sections 241.2(1)(e) and 241.2(7) of Bill C-14 require that health care providers obtain informed consent. In Ontario, the *Health Care Consent Act (HCCA)* requires that a person's consent is informed if the person receives information in respect to the nature of the treatment, the expected benefits of the treatment, the material risks of the treatment, the material side effects of the treatment, **the alternative course of action**, and the likely consequence of not having the treatment.⁶ In order to meet the *HCCA*'s requirements, a person who seeks a physician assisted death must receive information about alternative courses of action, including access to palliative care or other means to remediate sources of vulnerability.

Health care providers are responsible for the accommodation of the disability-related needs of their patients, including pursuant to statutory human rights instruments. In particular, the communication of the full range of available treatments, technologies and supports must take into account disability-related barriers to communication. Persons

⁶*Health Care Consent Act*, 1996, SO 1996, c 2, Sched A, at s 11.

with disabilities - including at end-of-life - have a right to accessible information about alternatives. Physicians and nurse practitioners must communicate information about these alternatives in an accessible manner that accommodates the person's disability related needs. This is particularly important for persons with communication disabilities.

Recommendation 2: Voluntary Consent Must Include Freedom from Coercion and Inducement

Presently, Bill C-14 only requires that physicians and nurse practitioners confirm that the request was made free from "external pressure." Without definition its application remains vague. Bill C-14 must clarify that a physician-assisted death is unavailable where external pressure **or any form of inducement** exists. Physicians or nurse-practitioners must be required to confirm that the persons who seek a physician assisted death do so voluntarily and without coercion. The lives of persons with disabilities are highly regulated, and they may depend on a variety of so-called "external" supports. Persons with disabilities are, in particular, vulnerable to inducement; a result of ableist stereotypes about their quality of life and prospects for recovery. Bill C-14 must clarify "external pressure" at s. 241.2(1)(d) to include explicit reference to "freedom from any form of inducement."

Conclusion

ARCH applauds the Preamble's affirmation of the "inherent and equal value of every person's life" and its commitment to protecting against "negative perceptions of the quality of lives of persons who are elderly, ill or disabled." We urge the inclusion of additional safeguards to deliver on these commitments. They must be more than rhetoric. Those safeguards, including the two outlined above, will guard against the perpetuation of the disadvantage and social vulnerability faced by persons with disabilities.

ARCH urges Bill C-14's adoption, with these additional safeguards, in advance of June 6 2016.