



Canada's only national political pro-choice advocacy group

POB 2663, Station Main, Vancouver, BC, V6B 3W3 • info@arcc-cdac.ca • www.arcc-cdac.ca

January 8, 2021

Re Bill 225, Harvey and Gurvir's Law (Provision of Information Respecting Down Syndrome)

Dear Standing Committee on Regulations and Private Bills,

The Abortion Rights Coalition of Canada would like to comment and make recommendations on the above-noted bill.¹ It is a commendable goal to ensure that pregnant people who have been given a fetal diagnosis of Down Syndrome are more accurately informed. We have no objection to requiring the Minister to produce written information on Down Syndrome as described in the added clauses for Section 3 of the *Regulated Health Professions Act, 1991*.

However, we object to Section 29.2 of the bill because:

- Mandating doctors by law to provide the written information is unnecessary, even counterproductive. The aim of the bill could be better achieved by working with the College of Physicians and Surgeons to disseminate the written information to its members, educate doctors and genetic counsellors, and issue policies and guidelines.
- Delaying prompt testing or treatment for patients is paternalistic, can have harmful impacts, and appears to be ideologically motivated to prevent abortion.

We want to make clear at the outset that people with Down Syndrome can live full, productive lives. A body of social science evidence shows that families who welcome a Down Syndrome baby typically find the experience rewarding and enriching.² Moreover, cognitive disability itself should not be seen as a negative thing. According to the Social Disability Model, disability results from the failure of society to accommodate individual needs. That is, people are disabled by barriers in society and discriminatory attitudes to difference, not by their impairment or the difference itself.³

Further, pregnant people with a fetal diagnosis of Down Syndrome should never be pressured or expected to have an abortion, and should never hear negative value judgments about the lives of people with Down Syndrome. But the premise of Bill 225, according to the stories of the families behind the bill,

¹ <https://www.ola.org/en/legislative-business/bills/parliament-42/session-1/bill-225>

² Chevalier, Meghan. Review of: Kaposy C. (2018) Choosing Down Syndrome. *Can J Bioeth.* 2019, 2(2):21-22. <https://www.erudit.org/en/journals/bioethics/2019-v2-n2-bioethics04449/1058145ar.pdf>

³ SCOPE – Equality for Disabled People. *Social model of disability.* www.scope.org.uk/about-us/social-model-of-disability/

is that expectant parents are being given biased, outdated, and erroneous information about Down Syndrome,⁴ leading to more people unnecessarily choosing termination.⁵

In the U.S., abortion rates for pregnancies with Down Syndrome are estimated to be about 67%⁶ (definitive Canadian rates are unavailable⁷). Even though some terminations may unfortunately result from misinformation or bias on the part of health providers, we must always respect peoples' decisions to have an abortion for whatever reason according to their own circumstances. We suggest that the solution is to educate healthcare professionals and society at large about the benefits of having a child with Down Syndrome. This is part of the project of reducing discrimination against people with disabilities more generally.

We worry that the bill and accompanying publicity (*see footnotes 4 and 5*) may itself be promoting a misleading message. While most people with Down Syndrome have mild to moderate versions of the condition, a significant minority have severe, even profound intellectual disability. Further, people with Down Syndrome are more predisposed to medical conditions such as congenital heart defects, immune disorders, leukemia, Alzheimer's disease, and others.⁸ The prevalence of congenital heart defects in newborns with Down Syndrome is about 44–58% worldwide.⁹ Since it is not possible to diagnose the severity of the condition prior to birth, pregnant people should be fully informed about the *range* of prognoses for a child with Down Syndrome – certainly, the many positive and hopeful aspects, but also the medical risk factors. It is not clear if this is the true intent of Bill 225, which seems inspired by anecdotal evidence from two families.

While some healthcare workers likely do exhibit bias or share misinformation at times about Down Syndrome, we must be careful not to paint all practitioners with the same broad brush. Healthcare workers have a professional obligation to act responsibly and ethically, and as a society, we should trust that most do so.

In cases where healthcare providers *do* impart incorrect information, it is doubtful that legislation is the best way to change behaviour. A law has the potential to interfere with medical discretion and the relationship between doctor and patient, doing harm to both. For example, a patient may value information less if they know the doctor is mandated to provide it, and the threat of prosecution seems overly chilling if doctors simply fail to provide information. Moreover, the desire to legislate around specific conditions in this manner tends to occur more with socially-contested issues like abortion and

⁴ Taylor, Nathan. Former city councillor 'emotional' to see Down Syndrome legislation reach Queen's Park. Orillia Matters. Nov 4, 2020. <https://www.orilliamatters.com/local-news/former-city-councillor-emotional-to-see-down-syndrome-legislation-reach-queens-park-2848824>

⁵ Swan, Michael. Bill aims to protect Down Syndrome babies. *The Catholic Register*. Nov 12, 2020. <https://www.catholicregister.org/item/32365-bill-aims-to-protect-down-syndrome-babies>

⁶ Global Down Syndrome Foundation. *Facts and FAQ About Down Syndrome*. <https://www.globaldownsyndrome.org/about-down-syndrome/facts-about-down-syndrome/>

⁷ Canada's Down Syndrome surveillance indicates that termination rates differ in different parts of Canada and also depend on the availability of fetal genetic testing, which is variable across Canada: <https://www.canada.ca/en/public-health/services/publications/healthy-living/down-syndrome-surveillance-2005-2013.html>

⁸ Mayo Clinic. *Down Syndrome*. <https://www.mayoclinic.org/diseases-conditions/down-syndrome/symptoms-causes/syc-20355977>

⁹ Weijerman EM, de Winter JP. The care of children with Down Syndrome. *European Journal of Pediatrics*, Vol 169, pp 1445–1452 (2010). <https://link.springer.com/article/10.1007/s00431-010-1253-0>

medical assistance in dying, which raises concerns that an ideological component is motivating this section of the bill.

We believe there are better alternatives than mandating doctors to provide written information (whether on Down Syndrome or other genetic conditions) – *improved education of healthcare professionals, and directives from the College of Physicians and Surgeons.*

Many doctors are likely ill-equipped to be having these conversations in the first place because medical schools fail to prepare doctors adequately. The amount of time they spend learning about fertility, reproduction, and disability is already minimal. How can doctors make informed recommendations around termination when abortion training is entirely optional? We suggest that the Ontario government work with the College of Physicians and Surgeons to develop new curricula and a continuing education course around enlightened disclosure of information for pregnant patients with a Down Syndrome fetal diagnosis. The College could also disseminate the Minister's written materials to their members, direct them to provide it to their patients when appropriate, and ask members to refer patients for genetic counselling¹⁰ if they lack the skills themselves. The College and/or the Canadian Medical Association could also issue a policy or guideline around the issue.

We strongly object to Section 29.2, subsections (2) and (3) for the following reasons:

- Restricting information about testing or treatment for 48 hours, even if this period can be waived, is paternalistic. This takes the decision for prompt treatment out of patients' hands and gives it to the doctor.
- It assumes that patients might make a "rash" decision so they need a "cooling off" period.¹¹ This is straight out of the anti-choice playbook¹² (mandatory waiting periods in the U.S.).
- It cannot be solely up to the doctor to decide what's medically necessary. Abortion decisions in particular belong to the patient alone, and all abortions are already deemed medically necessary by provinces and territories.
- The clause would restrict timely medical options for patients. If a patient makes a firm decision about treatment before the 48 hours elapses, the clause imposes an unnecessary delay that can have ripple effects due to delays in obtaining medical testing or appointments.
- The clause may privilege patients who are more assertive or have more knowledge about their right to information.
- Pro-choice doctors might be more willing to disclose full options to their patients, while anti-choice doctors may use the law as an excuse to hold back, resulting in withheld treatment based on the provider's personal beliefs and not patient needs.
- The optionality of the clause seems oddly placed within a law. Laws are about mandating behaviour, not making adherence optional or allowing discretion via a menu of options. This

¹⁰ International Center for Ethics, Justice and Public Life, Brandeis University. *The Ethics of Prenatal Testing for Down Syndrome: Is Knowing Always Better?* June 2015. <https://www.brandeis.edu/ethics/ethicalinquiry/2015/June.html>

¹¹ Taylor, Nathan. Former city councillor 'emotional' to see Down Syndrome legislation reach Queen's Park. *Orillia Matters*. Nov 4, 2020. <https://www.orilliamatters.com/local-news/former-city-councillor-emotional-to-see-down-syndrome-legislation-reach-queens-park-2848824>

¹² Guttmacher Institute. *Waiting Periods for Abortion*. January 2020. <https://www.guttmacher.org/evidence-you-can-use/waiting-periods-abortion>

indicates a possible hidden agenda behind this attempt to legislate the issue – specifically, the desire to restrict abortion.

Indeed, we believe that Section 29.2 is the first step to restricting abortions based on reason. Two U.S. states have banned or attempted to ban abortions for reasons of Down Syndrome,¹³ which points to a similar anti-choice motivation behind Bill 225. Our abortion rights group heard from two supporters about the problems with this bill, and both voiced the same concern that the bill could jeopardize reproductive rights in Canada. They are worth quoting:

Jenna Mitchell: “I am fine with informed consent, but as someone that couldn’t get an abortion until 19 weeks due to the long process of testing, results, and consultations, I feel this can endanger women’s lives and cause unnecessary delays for those that would have chosen abortion anyway.”

Supporter 2: “I am a genetic counsellor and have these conversations with women frequently. I am trying to understand the rationale to control conversations around this topic in a medical setting and I keep coming back to this being the first step towards limiting a woman's right to decide, and that this legislation is based on the dangerous assumption that medical professionals are currently not offering accurate information and that a woman needs 48 hours to reconsider her options. This is a dangerous start at chipping away at the reproductive rights of ON women.”

In conclusion, we oppose Section 29.2 of Bill 225 and recommend that it be entirely struck from the bill. Subsections (2) and (3) have a paternalistic bias that can harm patients and an underlying anti-choice motivation that seeks to limit the right to abortion. We oppose subsection (1) because if the Minister is mandated to develop written information on Down Syndrome, this should not extend to legislating that doctors must provide it to patients under penalty of law. Better solutions are to improve education for healthcare professionals, and task the College of Physicians and Surgeons with disseminating information and producing new directives and policies.

Thank you for considering our submission and recommendations.

Sincerely,



Joyce Arthur
Executive Director
604-351-0867
joyce@arcc-cdac.ca

¹³ Ohio: <https://www.nbcnews.com/news/us-news/down-syndrome-abortion-fight-ohio-takes-legal-twists-n1155276>.
Tennessee: <https://www.cnn.com/2020/11/22/us/tennessee-down-syndrome-abortion-ban/index.html>