

Harvey and Gurvir's Law: Ontario Bill for Quality Prenatal Information about Down Syndrome: Terminology, Feasibility, and Ethical Issues

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Abstract: Harvey and Gurvir's Law is a bill proposed to the Legislative Assembly of Ontario (Canada) to reduce stigma and bias associated with Down syndrome, by developing and disseminating quality information about Down syndrome in the context of prenatal testing.

In November 2020, the Legislative Assembly of Ontario heard the first reading of Harvey and Gurvir's Law (Provision of Information Respecting Down Syndrome).¹ Aiming to “end the bias and stigma associated with a prenatal diagnosis of Down syndrome,”² Bill 225 included two components: 1. Ensuring that clinicians provide “up-to-date, evidence-based information relating to Down syndrome”

to expectant parents receiving a prenatal Down syndrome diagnosis, and 2. Ensuring that clinicians leave a 48-hour waiting period after providing this information, before “recommending any further testing or treatment in relation to the diagnosis of Down Syndrome.”³ In June 2021, Harvey and Gurvir's Law was reintroduced as Bill 304. In this new iteration, there was no mention of a waiting period between test results and conversations about the next options.⁴ Bill 304 was reintroduced in March 2022 as Bill 101⁵ and has not been debated in second reading before the end of that Parliament Session. A new iteration of the bill could be introduced anytime.

Similar state laws prescribing the kind of information that needs to be provided to future parents in the context of prenatal testing have been adopted in the United States (US) under the umbrella term “Down Syndrome Information Act” (DSIA).⁶ In this essay, we draw upon the US experience and our academic and professional backgrounds, to highlight possible pitfalls in the potential implementation of Bill 101 and

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discuss the relevance of a waiting period. First, we place our arguments in the appropriate historical and current legal perspective by briefly discussing the legal context surrounding abortion in the US and in Canada. Second, we address the notion of quality information, by highlighting the ethical and implementation challenges of information laws. We move on to our analysis of the waiting period idea: we explain why the wording chosen for Bill 225 undermined the objective of decreasing stigma and bias and discuss the impact of a waiting period before presenting further options for both clinicians and patients. We conclude with suggestions for a formulation of the bill that does include a form of waiting period after test results to

and therefore violated the Charter of Rights and Freedoms.¹⁰ Since healthcare falls under provincial and territorial jurisdiction, Canada has 13 different publicly funded healthcare systems that regulate the provisions of reproductive rights.¹¹ Ontario is one of the only provinces or territories that did not implement restrictions on access to abortion as a result of Morgentaler's landmark decision¹² and *Murphy's v Dodd case* in 1989, where Gregory Murphy wanted to prevent Barbara Dodd, his former partner, from accessing abortion. Abortion rights are therefore not currently challenged in Ontario.

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allow future parents to make an informed choice, while staying in line with the stated aim of decreasing bias, a more feasible implementation and free choice.

Abortion Laws, Prenatal Testing and the Information Debate

The ruling in *Dobbs v. Jackson Women's Health Organization*, in which the US Supreme Court ruled that there is no constitutional right to abortion,⁷ has rendered DSIA's obsolete or at least significantly diminished their impact in States that implement strict abortion bans. First, the earliest available prenatal tests cannot be performed early enough in pregnancy to allow for an informed decision to be made about pregnancy continuation⁸ in states that impose gestational age limits for abortion. Second, expectant parents are less likely to seek early prenatal care or prenatal genetic testing if they fear that a pregnancy loss after a prenatal screening result⁹ may raise suspicions that they may have had an illegal abortion. However, comparisons and analysis of lessons learned from the implementation of DSIA's pre *Dobbs v. Jackson* in the US remain relevant.

It was not until a 1988 decision, *R. v Morgentaler*, that Canada officially decriminalized abortions, following an appeal heard by the Supreme Court, in which it was argued that the existing abortion legislation violated a woman's right to life, liberty and secu-

tier test in the 1st or 2nd trimester, as well as non-invasive prenatal screening (NIPT) as a 2nd-tier test for at-risk individuals and invasive diagnostic procedures (amniocentesis or chronic villus sampling). At the end of this process, abortion is presented as an option and is readily available to those who make this choice. It should be noted that in Canada, a pregnant person presenting for an abortion is under no obligation to mention their reasons for wanting to terminate the pregnancy.¹³ It is therefore impossible to know how many terminations are performed as a result of a screening or diagnosis of Down Syndrome. However, it is estimated that 60 to 90% of people with a positive diagnosis choose to end the pregnancy.¹⁴ Bill 101 is the first time in Canada's history that a provincial or territorial legislative authority has attempted to inform the discourse of clinicians following a Down syndrome screening or diagnosis.

Bill 101 is based on the idea that many clinicians are currently providing to expectant parents “outdated, incorrect or biased information based on antiquated models of disability, causing both misinformed reproductive decisions (i.e., terminating the pregnancy), and exacerbated discrimination and stigma related to people and families living with Down syndrome.”¹⁵ In the US, DSIA's use the same language and set the same objective of providing more accurate and balanced information that includes the perspective of families

living with Down syndrome.¹⁶ The federal legislation that preceded the states' DSIA and most of the DSIA themselves stemmed exclusively from the work of disability advocacy groups and disability rights scholars.¹⁷

We take this opportunity to clarify the distinction between these pro-information and anti-discrimination critics of prenatal testing, and anti-abortion arguments. Disability advocacy in this regard aims to reduce the stigma and discrimination experienced by families living with Down syndrome, not to restrict women's right to abortion. Like disability advocates,¹⁸ we deplore that some states' DSIA seem to have been misappropriated as anti-abortion tools. The arguments we make in this essay, therefore, aim to highlight the voice of disability advocacy in matters of prenatal testing, as it seeks to decrease the experienced stigma for families living with Down syndrome. Our arguments do not support any form of restriction on abortion rights.

Evidence-Based And Balanced Information

Previous work has shown that endeavors to develop balanced informational tools with regards to Down syndrome were indeed welcome in the spirit of fostering expectant parents' reproductive autonomy and decreasing the stigma associated with disability.¹⁹ Based on the social model of disability, some disability scholars and activists do not see disability in general — and Down syndrome specifically — as something that, in and of itself, negatively affects someone's well-being. These scholars and activists are usually those who militate for legislation about balanced information. It follows that many of these people do not see Down syndrome as a condition that needs to be screened, diagnosed, avoided through abortion, or cured. In addition, families of people living with Down syndrome often report that the information provided by clinicians is overly negative and does not accurately depict their lived experience of Down syndrome.²⁰ The goal of these information laws is to ensure a representation of the view of disability advocates and families living with Down syndrome, to balance out the more negative medical view that describes the array of medical conditions a baby may have. Research has shown that more experiential information is also desired by expectant parents.²¹

Unfortunately, DSIA seem to have yielded suboptimal results with regard to the quality and neutrality of the information provided and the quality of counseling in general. For instance, analysis of the information documents prepared after the adoption of the Pennsylvania DSIA and interviews with expectant parents have shown that the content of the material

and the quality of the counseling had not changed significantly.²² Of note, both Bill 101 and DSIA state that the informational material must be approved by both Down syndrome advocacy groups and medical experts.²³ Unfortunately, the involvement of advocacy groups in itself did not yield satisfactory results with regard to the inclusion of positive and experiential information that they deem important to balance out the negative medical information provided by medical experts. Funding for the development of appropriate material has been identified as the main factor to facilitate a real improvement in the nature of the information provided.²⁴

Poor compliance from practitioners may also be responsible for biased counseling despite the availability of adequate information support. A survey conducted in Ohio showed that 85% of parents who had a child with Down syndrome after the passing of the DSIA did not receive the state's Down syndrome fact sheet from their practitioner.²⁵ Other practitioners may provide the tools while expressing their own negative opinions about them to expectant parents.²⁶ Therefore, budget and implementation considerations, including proper training of health professionals, should be planned prior to the implementation of Bill 101. Imposing sanctions for non-compliance may also be considered.²⁷

Most DSIA also mandate the provision of contact information for local support and advocacy groups to encourage expectant parents to contact them and seek their perspectives. Bill 101 does not include such a provision and we suggest adding it, provided that local groups are willing to take on this responsibility. Such information may contribute to balanced information and informed choice but may also impose an additional burden on local support and advocacy groups, who may not have sufficient resources to respond to this added task.²⁸

Waiting Periods Between Discussions

The idea of waiting periods after providing results and before discussing the options for the next steps may have stemmed from anecdotal information regarding expectant parents finding out at the time of learning about a positive screen or diagnostic result, that their appointment for prenatal diagnosis or pregnancy termination was already booked or was readily available a few hours later. Such an "opt-out" scheme may indeed be problematic because it arguably implies that the "normal" or "expected" course of action is to undergo prenatal diagnosis and pregnancy termination. This practice runs contrary to an earlier counseling best practice recommendation to leave time for

people to process information and grief before making a decision.²⁹

We argue that there were important shortcomings in the formulation of the 48-hour waiting-period provision in Bill 225, including the choice of words used and the strict imposition of the waiting period. We suggest that these problems could have been resolved by reformulating the provision in Bill 101, rather than entirely removing the notion of a waiting period.

Counterproductive Word Choices

While Harvey and Gurvir's Law aims to reduce stigma, biases, and misconceptions about Down syndrome in the general population and expectant parents, the wording proposed in Bill 225 appeared contrary to this endeavor:

29.2 (2) After providing the information under subsection (1), the member shall not, until 48 hours have elapsed since the information was provided, **recommend** any *further testing* or any **treatment** in relation to the diagnosis of Down syndrome unless *explicitly* requested by the expectant parent or parents or unless the member is of the opinion that it is **necessary** to perform the testing or treatment during the 48-hour period.

First, we wish to stress that the words "recommend" and "necessary" are inappropriate in this context. Prenatal screening, prenatal diagnosis, and pregnancy termination should never be *recommended* by clinicians. The Society of Obstetricians and Gynaecologists of Canada (SOGC) clearly states that prenatal screening and diagnosis must be *offered* to expectant parents and that expectant parents may choose to use them or not.³⁰ Likewise, the option of terminating the pregnancy is a choice that belongs to expectant parents, and should not be a medical recommendation. It follows that none of these procedures are ever *necessary*. Ironically, by using such words, Bill 225 itself would have contributed to stigmatization and bias, by endorsing a vocabulary that attributes undue power to those misinformed clinicians who would *recommend* or deem *necessary* further testing or pregnancy termination based on their own misconceptions regarding Down Syndrome.

Second, the word "treatment" is misleading. There is currently no treatment available prenatally for Down syndrome. After birth, treatment or supportive therapies are available for specific health conditions associated with a Down syndrome diagnosis. While there is ongoing research on possible therapies to

"cure" Down syndrome,³¹ some of the same advocates who currently request information laws may actually oppose, or express skepticism, about the possibility of a treatment that would remove Down syndrome traits, as they do not perceive these traits as medical conditions that require curing.³² Since the goal of this bill was to tackle discrimination and bias against people with Down syndrome, construing pregnancy termination following a Down syndrome prenatal diagnosis as a "treatment" was highly counterproductive.

The desire to avoid the term "pregnancy termination" may have stemmed from a need to avoid this politically fraught topic. To be clear, Harvey and Gurvir's Law and most DSIAs are pro-information and anti-discrimination laws, not anti-abortion laws. In the US, some of the most conservative states have unfortunately explicitly included in their DSIA a provision instructing clinicians not to bring up pregnancy termination as an option, following a positive prenatal testing result. In addition to exposing clinicians to wrongful birth lawsuits in the US context, such instrumentalization of the pro-information and anti-discrimination debate pertaining to Down syndrome to promote an anti-abortion agenda seems to have caused undue criticism of DSIAs in general.³³ Since Canadian laws are clear and decisive about access to abortion, there should be no need to avoid mentioning it clearly in legislative texts.

Therefore, in any future iteration of this bill or other legislation regarding prenatal testing, we suggest avoiding terms that imply that prenatal testing is "recommended" or "necessary," or that pregnancy termination is a "treatment."

Problems with 48-Hour Waiting-Periods

Prenatal *testing* includes both prenatal *screening* and prenatal *diagnosis*. In addition, NIPT (non-invasive prenatal testing), is sometimes mistakenly understood as *diagnosis*, while it is actually a type of *screening*. The difference is that a screening test provides only a probability while a diagnostic test provides a definite result. In addition, screening tests use non-invasive technologies such as ultrasound and blood tests, while diagnostic tests use invasive procedures involving a slight risk of miscarriage, namely amniocentesis or chorionic villus sampling. After a positive screening result, expectant parents who wish to know with certainty are advised to confirm the results by a diagnostic test before making final decisions. This includes those who would consider terminating the pregnancy if the fetus had Down syndrome.

In Bill 225, "further testing" was mentioned alongside "treatment." This formulation leaves unclear

whether the 48-hour waiting period should occur after the screening result, before discussing the possibility of undergoing prenatal diagnosis (further testing), or only after prenatal diagnosis, before discussing the possibility of terminating the pregnancy (“treatment”). This was particularly problematic considering the above-mentioned confusion with NIPT. Indeed, “further testing” to confirm the results is only offered after a positive prenatal screening result, while “treatment” (i.e., pregnancy termination) is offered after a positive prenatal diagnostic result. We will assume that the 48-hour waiting period applied to both positive screening and diagnosis and address the issues that pertain to each of them. Of note, most DSIA do explicitly apply to counseling following both screening and diagnosis.³⁴

After a positive *screening* result, up-to-date and balanced information about Down syndrome is necessary to help people decide if they wish to undergo prenatal diagnosis despite the risk of iatrogenic miscarriage. After a positive *diagnosis*, this information is also necessary as this is the point where expectant parents must choose if they wish to raise a child with Down syndrome, end their pregnancy or place the baby for adoption. However, in both cases, the need for and practicality of a 48-hour waiting period before *merely discussing* the possible next steps is debatable. Indeed, this waiting period is decisively impractical for clinicians and expectant parents alike who would need to meet again for another appointment 48 hours later. In addition to logistical issues, this leaves the parents in limbo about the situation for 48 hours or even more, depending on scheduling considerations. In fact, most expectant parents will *explicitly request* to discuss what the next steps may be, rendering the 48-hour waiting-period provision pointless. We suspect that these issues contributed to the decision to remove this requirement when this bill was reintroduced in the Legislature as Bill 101.

However, there may have been value in simply applying the waiting period to *booking* an appointment for prenatal diagnosis or pregnancy termination, provided that appointments are readily available afterward, as opposed to *merely discussing* it. Arguably, this would allow expectant parents to process the information they were provided about Down syndrome. They may also use the time to seek further information by contacting local advocacy groups, discuss it with family members and weigh their options carefully. This may contribute to a well-thought-out decision about prenatal diagnosis or pregnancy termination. A waiting period between receiving a screening result and booking prenatal diagnosis, or between

receiving a diagnostic result and booking pregnancy termination, therefore arguably promotes informed choice. As such, it may be beneficial in terms of reproductive autonomy which is, after all, the very essence of prenatal testing.

It could be argued that some expectant parents already have their mind set on undergoing prenatal diagnosis or terminating a pregnancy by the time they get to that point. Further, they may place value on accessing these services as soon as possible for the benefit of avoiding a later pregnancy termination that may involve more psychological and physical consequences. Whether these decisions are based on misconceptions or not, it appears contrary to autonomy considerations of free choice to voluntarily thwart their projects by hindering rapid access to these services. In Canada, any person can legally obtain a pregnancy termination at any stage of the pregnancy and irrespective of her reasons. Consequently, it could be considered unfair, and legally questionable, to *impose* a waiting period specifically for those who seek a pregnancy termination after a positive prenatal diagnosis.

Clinical experience suggests that when there are delays in obtaining an appointment for prenatal diagnosis, some expectant parents prefer to terminate the pregnancy based on the result of prenatal screening alone. This may result in the abortion of fetuses without a chromosomal aneuploidy. We acknowledge that such decisions may often be based on misconceptions. As such, it is a symptom of the misconception/bias/discrimination problem that Harvey and Gurvir’s Law aims to tackle as much as it is a dire consequence of delays in accessing prenatal diagnosis. In addition, we do not suggest that the loss of a [potentially] neurotypical baby due to misconceptions is worse than the loss of a baby with Down syndrome due to misconceptions. However, decisions to undergo prenatal diagnosis and to terminate a pregnancy because of Down syndrome, even when taken rapidly, are not always based on misconceptions. Therefore, *imposing* a waiting period for obtaining services appears like an inadequate “one-size-fits-all” solution that may promote *informed* choice but may also hinder *free* choice, another important component of reproductive autonomy. We suspect that these legal and ethical aspects were also considered in the decision to remove the provision from the bill.

We previously discussed the notion of “recommendation” in the context of prenatal testing by saying that prenatal testing for Down syndrome should be *offered* to expectant parents, as opposed to being *recommended*. We argued that the language of “recommendation” refers to clinicians’ power of persuasion

that needs to be used carefully when it comes to personal choices. In the spirit of Harvey and Gurvir's Law which aims to promote *informed* choice with regard to prenatal diagnosis and/or pregnancy termination in the face of common misconceptions about Down syndrome, clinicians should not *recommend* undergoing prenatal diagnosis or terminating a pregnancy. However, they may very well *recommend* that expectant parents take a few days to ponder their options in light of the information about Down syndrome provided by their practitioner and obtained from other sources, before booking an appointment. This would encourage people to take time to make an informed choice, without constraining *free* choice by preventing rapid access to services for those who do want to act more promptly. We certainly do not suggest that expectant parents be invited to take time to ponder the rightfulness or wrongfulness of abortion, but rather to take time to gather information relevant to their decision-making. For example, they may wish to access up-to-date, diverse, and balanced information about what it means to raise a child with Down syndrome to inform their decision regarding the management of their pregnancy.

Based on the above terminological, legal, and ethical considerations, we suggest that the 48-hour waiting-period provision could be reformulated and reintroduced in a third iteration of Harvey and Gurvir's Law. We make the following proposal:

(2) After providing the information about Down syndrome described under subsection (1), the member will recommend that expectant parents take a few days to make an informed decision about the next steps, unless the window of opportunity for these decisions may close during this period. The member will grant access to further testing or pregnancy termination based on availability whenever expectant parents request them.

Conclusion

Harvey and Gurvir's Law aims to fight stigma, biases, and discrimination and promote informed choice with regard to prenatal testing and subsequent pregnancy termination. Similar laws have previously been adopted in the US with sub-optimal results. Possible avenues to more decisive changes to information provision include adequate budgets and strategies to ensure successful implementation, proper training of clinicians, and adequate resources for them to adopt the recommended practices.

The idea of waiting periods between providing prenatal screening results and booking prenatal diagnosis, and between providing diagnostic results and booking pregnancy termination, has value for promoting reproductive autonomy and reducing stigma. However, the 48-hour waiting-period provision of Bill 225 was worded in a way that ran contrary to its objective to reduce stigma. In addition, practical, legal, and ethical considerations may have motivated the removal of this provision in Bill 101. Alternatively, we suggest that Harvey and Gurvir's Law could demand that clinicians *recommend* taking a few days to make an informed choice, but definitely not *require* it.

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