

COMMENTARY

Harvey and Gurvir's Law: The Need for Accurate Information Balanced Against Avoiding Unnecessary Restrictions on Autonomous Decision Making

Louise P. King¹

1. HARVARD MEDICAL SCHOOL, BOSTON, MA, USA.

Keywords: Harvey and Gurvir's Law, Autonomy, Decision Making, Consent, Stigma, Disability.

Decision making during reproduction is complex for a variety of medical and social reasons. Anyone who has had a conversation with a family member about the “best time” to have a baby can attest to this — there is no “best time” or “best way.” Multiple pressures from any number of sources combine in a minefield of hazards made ever more complicated by restrictive laws in the US. Add to this a screening result of potential chromosomal aneuploidy and decision making becomes ever more complex. Societal stigma and lack of adequate and accurate information during counseling certainly plays a role in the high number of terminations in the setting of diagnosed chromosomal aneuploidy, yet other factors also push families in this direction including medical considerations and the abysmal lack of social support programs.

In their review of Harvey and Gurvir's Law, Lemoine et al.¹ here address one legislative response to societal stigma against persons with disabilities. The professed goal of this legislation is to ensure informed decision making ahead of termination in the setting of chromosomal aneuploidy. Legislation proposed in Canada and existing in the US requires dissemination of accurate information about the diagnosis and prognosis in the setting of chromosomal aneuploidy, in some cases specifically trisomy 21. A waiting period

Louise P. King, M.D., J.D., is an Assistant Professor of Obstetrics, Gynecology, and Reproductive Biology at Harvard Medical School.

ahead of termination is sometimes required. Yet, none of the legislation to date meaningfully funds proposed and necessary educational interventions nor truly addresses the optimal way to encourage changes in behaviors as suggested by experts and behavioral science.² While the authors of this piece expertly navigate discussion of a proposed law in Canada with reference to ethical considerations, I see insurmountable issues with this type of unfunded legislation.

Lemoine et al. initially focus on the language used in the bill, and their critiques are well founded. Although they object specifically to any “recommendation” of termination by a clinician, there are a wide variety of legitimate reasons for potentially recommending pregnancy termination in the setting of testing revealing chromosomal aneuploidy. These reasons may be separate and apart from any tendency towards ableism. A legal “ban” on using the term “recommend” as it applies to pregnancy termination would be too broad. Clinicians are frequently asked explicitly by patients for their recommendation in any given clinical scenario. Legally restricting the delivery of recommendations is problematic.

In a similar vein, I agree with the authors suggestion that clinicians “may ... recommend” [emphasis added] pregnant persons and families take time before making a final decision regarding diagnosis and/or termination — in appropriate circumstances. Yet, a proposal to encapsulate this in legislation — and use of the term “will recommend” [emphasis added] in proposed language — could force clinicians to violate the autonomy of their patients.³ The authors concede “some expectant parents already have their mind set on undergoing prenatal diagnosis or terminating a pregnancy by the time they get to that point.” In truth,

reliable research suggests that most expectant parents arrive with a decision already made in reference to termination.⁴ Whether these decisions are the result of ableist beliefs, or a variety of other concerns or priorities, cannot be said definitively. What is essential and not for debate is that clinicians' primary duty will be to the pregnant person and ensuring respect for their autonomous decision. If clinicians have not provided clear and accurate information about the screening result or the nature of a particular chromosomal aneuploidy, that is a failure. There is much work to be done in educating clinicians and ensuring we proceed from a less ableist lens. Yet, it is impossible to turn back the clock when sitting in front of a specific patient who has already made a decision. Forcing patients to wait

als. Yet, this type of adjustment in training and delivery of counseling will take time and money, factors that are rarely if ever addressed by current legislation.

Could we not direct our efforts and funding to education in ways that might be more effective? Mandating clinicians adequately educate patients about chromosomal aneuploidy while making no required changes to insurance funding for that education means that clinicians will inevitably be forced to convey complex information in excessively short time frames. Failure to adequately communicate to patients on such subjects to date is likely explained at least in part by this lack of funding and protected time. A different and more effective approach would be to legislatively mandate changes in insurance funding for appointments

Legislation that addresses the needs of families and persons with disabilities is essential. Many families make choices around termination given a lack of funds to care for future children and adults potentially in need of lifelong care. None of these legislative efforts seem to acknowledge these realities.

While it can be difficult to pass funded legislation at least through the US Congress, without adequate supports put in place, it is unclear how any unfunded mandate or suggested waiting period will create meaningful change and instead runs of the risk of causing further harm.

by law is not consistent with an ethical duty to them *in that moment*. If the goal is to ensure that pregnant persons are incentivized and supported to see the value in continuing pregnancies with chromosomal aneuploidy and raising children with disabilities, legislators must not then create a law that perpetuates stigmatization of those same pregnant persons and restricting their decision making or requiring any recommendation that they wait.

I share the goals of these authors, of those who proposed these bills and similar ones in the US and of advocates who wish to ensure that stigma for those with disabilities is fought and mitigated. I agree the information currently provided to families is not adequate or accurate. I see benefit in mandatory compassionate non-biased delivery of accurate information. But I wonder who is best suited to deliver this information, in what time frame, and in what context? Experts suggest the ideal source for delivering this counseling is “[h]ealthcare professionals who have an understanding about real-life experiences of people with disabilities and their families”⁵ and that training is sorely needed for clinical students and profession-

that afford adequate time for such counseling by either specifically trained obstetricians or genetic counselors. Further funding could be legislatively required to develop educational coursework for clinicians to combat prior ableism. Finally, legislation that addresses the needs of families and persons with disabilities is essential. Many families make choices around termination given a lack of funds to care for future children and adults potentially in need of lifelong care. None of these legislative efforts seem to acknowledge these realities. While it can be difficult to pass funded legislation at least through the US Congress, without adequate supports put in place, it is unclear how any unfunded mandate or suggested waiting period will create meaningful change and instead runs of the risk of causing further harm.

Note

The author has no conflicts of interest to disclose.

References

1. M. E. Lemoine, et al., "Harvey and Gurvir's Law: Ontario Bill for Quality Prenatal Information about Down Syndrome: Terminology, Feasibility, and Ethical Issues," *Journal of Law, Medicine & Ethics* 51, no. 3 (2023): 651-657.
 2. Brackett et al., Prenatal Subcommittee of the Center for Dignity in Healthcare for People with Disabilities, "Recommendations to Improve the Patient Experience and Avoid Bias when Prenatal Screening/Testing," *Disability Health Journal* 16, no. 2 (2023): 101401.
 3. *Id.*
 4. See <<https://www.ansirh.org/research/ongoing/turnaway-study>> (last visited September 8, 2023).
 5. Brackett et al., *supra* note 2.
-