POSITION

WRITTEN BY: **We *Need* a Law**

ABORTING *those who are* DIFFERENT

Fetal abnormalities generally, and Down syndrome specifically, have gone from an exception in abortion restrictions to a presumption that parents will choose abortion.

When a woman found out that one of her 32-week-old pre-born twins had a congenital heart defect that would likely require numerous operations, she decided to abort the one and give birth to the healthy twin. The physician, however, gave the lethal injection to the wrong child.[1] In the end, both twins lost their lives. If the abortion had gone as planned, this would not have been considered a newsworthy story. If the child with a disability had been aborted and the mother had given birth to the healthy twin, this would have been considered another successful abortion – and a standard way to treat prenatal diagnoses like this one.

The rate of selective abortions – that is, abortion chosen because of traits in the pre-born child rather than circumstances of the parents – has increased in correlation with the ability to learn more about the child in the womb. The development of in-depth prenatal testing and genetic counseling have resulted in increased selective terminations, as evidenced in Iceland where they claim to have nearly "eradicated" Down syndrome.[2] Fetal abnormalities generally, and Down syndrome specifically,

have gone from an exception in abortion restrictions to a presumption that parents will choose abortion.

This presumption in favour of abortion for fetal abnormalities needs to be examined and questioned. Even for those who do not recognize the humanity of the pre-born child the question remains: is every choice beyond questioning?[3] An individual choice cannot be an end to the conversation. There must be room to consider the negative ramifications for the parents, those living with similar conditions, and of course the pre-born child.

THE INDIVIDUAL AND THE CULTURE

The choice to terminate a pregnancy is often characterized on an individual basis. And while it is true that these choices are made by individuals, they cannot be divorced from the surrounding culture – a culture that includes unique and differently abled persons. Individuals are impacted by the culture they are in, and culture is impacted by the choices individuals make. As one scholar put it, choice "is not exercised in a social vacuum; it is exercised only within the parameters set not only by law but also by social norms."[4] The impact of choice in the context of selective abortions for fetal abnormalities has practical ramifications from reducing the number of persons with these conditions as well as broader ramifications in terms of how we value those who struggle with their health, who are dependent, or who are different.

THERE ARE FEWER PERSONS

In Canada today, there are fewer born persons with disabilities or genetic conditions due to the prevalence of prenatal testing and abortion. This is acknowledged by many Canadian authorities, including the Canadian Institute for Health Information which explains the decline of the rate of those with Down syndrome as being due to various factors including "the availability and use of prenatal screening and diagnosis, and the rate of pregnancy termination."[5]

The fact that there are fewer persons with conditions like Down syndrome has ramifications beyond the individual. Chris Kaposy, a pro-choice associate professor of bioethics in the Faculty of Medicine at Memorial University, notes the predicament this places those with Down syndrome in, saying, "A greater number of people with Down syndrome would bring with it a greater number of ambassadors and advocates advancing their

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interests, reducing bias, supporting social inclusion, better housing, and better employment."[6] This has very practical considerations, including resource allocation to prenatal screening instead of toward improving the lives of those with these conditions.[7] The reality is, having fewer persons with a certain condition means we have less opportunity or perceived need to better their care.

THE WAY OUR CULTURE VALUES THOSE WHO ARE DIFFERENT

As a nation, Canada seeks to ensure equality rights and condemns discrimination on the basis of disability. This is grounded in the *Canadian Charter of Rights and Freedoms*,[8] Canadian human rights law,[9] and the *United Nations Convention on the Rights of Persons with Disabilities*, under which Canada has committed to raising awareness and to combatting stereotypes relating to persons with disabilities.[10] We need to emphasize these commitments here in Canada, remembering that children with disabilities or genetic condition are not social liabilities.

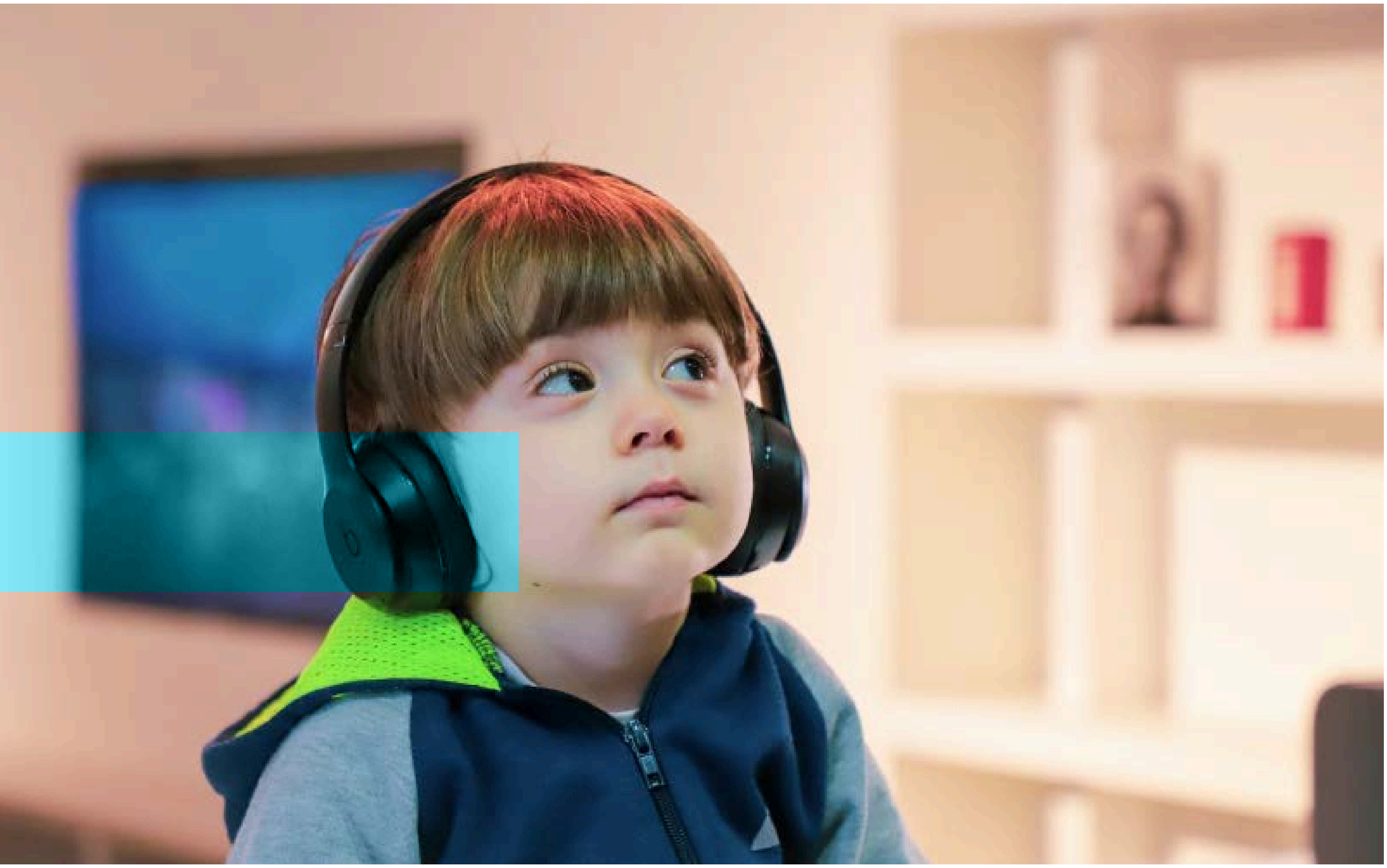
Facilitating, and even encouraging, abortion due to fetal abnormalities promotes a view that these lives will necessarily be harder and of lesser quality, or that these persons are a burden to those around them. It lends itself to an ableist lens where we value only able-bodied, healthy, independent lives. This stigma, which begins at the way we treat a prenatal diagnosis, has a negative impact on the well-being and self-esteem of those living with Down syndrome and other conditions.[11]

The choice to abort due to a fetal abnormality might be made by an individual, but impacts are felt by all with the same condition. This creates a cycle – parents choose to terminate those with a certain condition, there are fewer persons with that condition, there is less acceptance and understanding, and so future parents face the same scenario. Kaposy explains, "If we lived in another culture that valued different things, we would not regard the diagnosis or birth of a child with Down syndrome, even initially, as a loss…These memoirs written by parents of children with Down syndrome not only present a different way of thinking about cognitive disability; they also force us to think about what kind of society we want to live in."

THE INDIVIDUALS MAKING THE CHOICE

While this choice might have broader cultural impacts, it has intense, immediate consequences for the parents. Choosing to abort, to place for adoption, or to parent a child with a fetal abnormality are all life-altering decisions. Emily Perl Kingsley compares such a life-altering decision to preparing to go Italy but ending up in Holland. You may have prepared by learning Italian and buying Italian guidebooks, but finding yourself at an unexpected destination you now need to learn a whole new language and find new resources.

But Kingsley encourages parents not to let the unexpected nature of the destination dominate their experience. "The important thing is that they haven't taken you to a horrible, disgusting, filthy place, full of pestilence, famine and disease. It's just a different place," she says. "If you spend



your life mourning the fact that you didn't get to Italy, you may never be free to enjoy the very special, the very lovely things ... about Holland."[12]

IT MATTERS HOW YOU ARE GREETED

Entering Holland, that is, receiving an unexpected prenatal diagnosis, comes with a whirlwind of emotions. However, too often these conversations begin with a professional saying, "I am so sorry," as Sarah Williams describes hearing when her third daughter, Cerian, was diagnosed with thanatophoric dysplasia – a lethal skeletal deformity. Within an hour of delivering this news, the consultant was suggesting dates for termination, seemingly as an obvious next step.[13] Similarly, Kim Kampen describes her experience with a doctor who, after explaining her ultrasound showed markers that indicated Down syndrome, declared that "Abortion is the only cure for Down syndrome."[14]

Tamara Taggert, in her Ted Talk, explains the experience of having a similar conversation shortly after her son was born, in which her doctor came to her with sadness to let her know that her son had an extra chromosome, describing all the things he would never do. It wasn't until after she had another conversation with her oncologist, who was kind, hopeful, and empathetic, encouraging her that she would beat cancer, that Taggert realize how wrong the conversations around her son had been. "My son is not cancer."[15]

If we are going to encourage parents to make a choice that values all regardless of ability, it needs to start in these first conversations. Parents arriving into this unexpected "Holland" need to be greeted with encouragement and support, not negativity and sorrow. This update to the conversation involves all of us – health care professionals, friends, and family. Do we view the existence of someone with a disability or genetic condition as something to mourn, or as a diversity to be treasured?

CHOOSING AN END

Choosing to parent a child with a fetal abnormality is undoubtedly a daunting path to take. It is a path filled with unknowns and unseen obstacles. Abortion, on the other hand, seemingly means choosing a quick end to a story. But it is not the end for parents. The Quebec Government website puts it simply when discussing options for parents facing a prenatal diagnosis: parents can "continue the pregnancy and prepare to be the parents" or they can ***"terminate the pregnancy and cope with the resulting grief."***[16] The prenatal diagnosis changes parents, regardless of their subsequent choices. Whether they choose to parent, with all the accompanying joys and struggles, or choose to end that life and deal with the grief, parents are impacted by the lives of their children, no matter how short.

In their literature review on this subject, Dr. Eoghan de Faoite and Nora Sullivan conclude that "abortion for reason of potentially fatal anomalies can have a lasting and negative psychological impact"[17] on parents. One of the studies reviewed pointed out that it was not just the difficulty of the decision to terminate or even the abortion itself that lead to a negative psychological impact. Rather researchers concluded, "The harshness of their loss seemed to be intensified by the fact it was 'chosen' by themselves."[18] Abortion does not end parents' grief for their lost child.

CHOOSING DIFFERENCE

Raising a child with a disability or genetic condition, as with raising any child, has its challenges. But it also has real joys and rewards. We often have preconceived notions of what the ideal life looks like, including the idea that we want "perfect" or "normal" children.[19] This can come from negative stereotypes, ignorance, or prejudices towards those who live with disabilities or genetic conditions.

Despite the experience of shock and grief at an initial diagnosis, parents of children living with conditions like Down syndrome speak with overwhelming positivity about the influence of their children on their lives. One survey of over 2,000 parents showed that 97% felt proud of their children and only 4% had any regret about the condition.[20] Kaposy compares this to the perceptions toward Down syndrome of the many who chose to abort after prenatal diagnosis, concluding, "This contrast suggests that many selective decisions are motivated by a lack of understanding about Down syndrome."[21] Parents who choose to abort may be overwhelmed by a daunting picture – but it is a picture that is missing the texture that those who parent experience.

Indeed, having a child with disabilities or genetic conditions can act as "a catalyst for a change in attitudes and values."[22] One of the reasons for this is that, prior to giving birth, a

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parent is likely to think only of the condition, at the expense of the human being with the condition. Robin Roach makes this point: "As I think back on the list of predictions that were made about [my son] Bryan, I see that some of them were accurate and many were not. More importantly, that list could not predict his personality, his unique attributes, and the way he affects the people around him."[23]

This theme repeats itself over and over again in stories of parents raising children with disabilities. Rather than regretting their lost ideal, parents describe the experience as one of learning for themselves – learning about joy, love, and the value of those who are dependent on others. One mother describes the joy she finds in learning the value of relationship and love over independence with these words:

> *"This is the part of us that makes our brief, improbable little lives worth living: the ability to reach through our own isolation and find strength, and comfort, and warmth for and in each other. This is what human beings do. This is what we life for, the way horses live to run."*[24]

A PERSON, NOT JUST A CONDITION

Sarah Williams was pro-life before she got the news of Cerian's likely fatal condition, but she describes the turmoil she went through when deciding whether to terminate or not. The principles she held seemed insufficient when she faced the real situation. As the pregnancy progressed, however, Sarah gained strength in the call she felt to love Cerian no matter how long she had her in her life. At one point a doctor asked Sarah, "Did you decide not to have a termination on strong religious grounds?" Sarah's instinctive response was to point out, "Cerian is not a strong religious principle or a rule that compels me to make hard and fast ethical decisions. She is a beautiful person who is teaching me to love the vulnerable, treasure the unlovely, and face fear with dignity and hope."[25]

Sarah saw the person Cerian was. Before her child's birth, Sarah worked through the "I'm so sorry" of her greeting to Holland, she waded through preconceived notions of the value of life marked by hardship and being different. In the end, Sarah made her decision based on the person Cerian was. Although Cerian did not live past her birth, never spoke to her parents, never went to school, and never had a job, Cerian was loved and valued. Sarah and her family recognized Cerian for the unique human being that she was and strove to love her every day they had with her. And their lives were better and fuller because of even the short time they got to spend with Cerian.

SELECTIVE TERMINATION: FATAL TO ONE

Abortion due to fetal abnormality is harmful to a society that wants to value those who are different. It provides an end to a chapter, but not to the grief that parents experience. It shuts the door on a life full of endless possibility as evidenced by the stories of parents who raise differently-abled children. But there is another fundamental concern: abortion is the ending of a human being's life. This is not to be mistaken with a passive letting a child die or refusing a treatment. Rather, it is the intentional ending of that child's life at a time chosen by the parent.

A child with a disability or a genetic condition is likely to face hardships. But avoiding those hardships by ending the child's life is not an appropriate answer. A parent's responsibility to their child is not to provide a life bereft of hardships. As one mother of a son with Down syndrome put it:

> *"I know your life is not easy. I know how many struggles you've had so far and I can't even fathom how many more you still have to face. I've learned that I can't take those away. As much as I'd like to protect you and shelter you and keep anyone from hurting you, it just isn't possible. More importantly, if I were able to take all of your problems away, you wouldn't be allowed to develop as a person.* ***Part of being human is our struggles and how we overcome them.****"[26]*

Parents have a legal responsibility to provide the necessities of life to their children, and they have a moral responsibility to provide more in terms of relational support, care, and love. But there is no duty to remove all hardships, as that is both an impossibility and counterproductive. Every parent who has watched their child struggle or suffer knows the desire to remove barriers. But removing all barriers denies a child the chance to grow and develop as a person. A child must stumble in order to learn to walk.

Choosing to carry a child with a fetal abnormality – whether it be for the short time they are alive or with a view to parenting a differently-abled child long-term – is a struggle. Cutting through the negative conversations, the overwhelming spectre of the condition, the cultural premium of independence and ability, and the struggle to see the person behind the condition will not remove all the hardships. But, "part of being human is our struggles and how we overcome them."

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REFERENCES

[1] Australia inquiry after wrong twin foetus terminated. (2011). *BBC News.* Retrieved from https://www.bbc.com/news/world-asia-15870161.

[2] Quinones, J., & Lajka, A. (2017). "What kind of society do you want to live in?": Inside the country where Down syndrome is disappearing. *CBS NEWS.* Retrieved from https://www.cbsnews.com/news/down-syndrome-iceland/

[3] Kaposy, C. (2018). *Choosing Down Syndrome.* Cambridge, MA: Massachusetts Institute of Technology ["Choosing Down Syndrome"] at p 5 holds this position saying "Though my position is pro-choice, I do not believe that personal reproductive decisions should beyond the reach of ethical reflection or examination."

[4] Mills, C. (2015). The Case of the Missing Hand: Gender,Disability, and Bodily Norms in Selective Termination. *Hypatia*, 30(1), 82-96 at p 83.

[5] Rockman-Greenberg, C., Avard, D., Hanvey, L., & Fitzpatrick, J. (2014). Section 5: Congenital anomalies. *In In The Health of Canada's Children and Youth: A CICH Profile.* Retrieved from https://cichprofile.ca/wp-content/uploads/2017/10/2.5-congenital-anomalies-en.pdf.

This is also acknowledged by the Public Health Agency of Canada. (2013). *Congenital Anomalies in Canada 2013: A Perinatal Health Surveillance Report.* Ottawa: "Prenatal screening has advanced in both accuracy and early detection such that it has had a significant impact on the [Down syndrome] live birth prevalence across all maternal ages, worldwide."

And in Navaneelan, T., Pearson, C., & Janz, T. (2016). Deaths from congenital anomalies in Canada, 1974 to 2012. In *Health at a Glance*. Statistics Canada. Retrieved from https://www150.statcan.gc.ca/n1/pub/82-624-x/2016001/article/14649-eng.htm which likewise offers an explanation for the decline in infant deaths as being influenced by the rate of "termination of pregnancies affected by major anomalies."

[6] Choosing Down Syndrome at p 8.

[7] Choosing Down Syndrome at p 7.

[8] *Canadian Charter of Rights and Freedoms*, s 7, Part 1 of the Constitution Act, 1982, being Schedule B to the Canada Act 1982 (UK), 1982, c 11 at s 15.

[9] Including prohibiting discrimination on the basis of "genetic characteristics, disability" under the federal *Canadian Human Rights Act* (R.S.C., 1985, c. H-6) at s 3.

[10] United Nations. *Convention on the Rights of Persons with Disabilities and Optional Protocol.* Retrieved from http://www.un.org/disabilities/documents/convention/convoptprot-e.pdf at Article 8.

[11] Paterson, L., McKenzie, K., & Lindsay, B. (2012). Stigma, Social Comparison and Self-Esteem in Adults with an Intellectual Disability. *British Institute of Learning Disabilities*, 25(2), 166-176.; and Jackson, C., Cavenagh, P., & Clibbens, J. (2014). Communication and Self-esteem in Adults with Down Syndrome. *International Journal of Language & Communication Disorders*, 49(3), 275-287.

[12] Kingsley, E. P. (1987). *Welcome to Holland.* Retrieved from http://www.our-kids.org/Archives/Holland.html.

[13] Williams, S. C. (2018). *Perfectly Human: Nine Months with Cerian.* Walden, New York: Plough Publishing House ["Perfectly Human"] at p 5.

[14] Kampen, K. (2019). *Pressure to Abort: A Mother's Story.* Retrieved from https://weneedalaw.ca/2019/01/pressure-to-abort-a-mothers-story/.

[15] Taggart, T. (2014). *Two conversations that changed my life.* TEDx Talks. Retrieved from https://www.youtube.com/watch?v=vjRlFCgQ1e8.

[16] (2020). *Trisomy 21 Prenatal Screening Program of Québec.* Gouvernement du Québec. Retrieved from https://www.quebec.ca/en/health/advice-and-prevention/screening-and-carrier-testing-offer/trisomy-21-prenatal-screening-program-of-quebec/. Emphasis added.

[17] Sullivan, N., & de Faoite, E. (2017). Psychological Impact of Abortion due to Fetal Anomaly:A Review of Published Research. *Issues in Law & Medicine*, 32(1), 19-30 ["Psychological Impact"] at p 26.

[18] Psychological Impact at p 26.

[19] Choosing Down Syndrome at p 43.

[20] As cited in Choosing Down Syndrome at pp 63-64.

[21] Choosing Down Syndrome at p 56.

[22] Choosing Down Syndrome at p 31.

[23] Roach, R. (2007). Oh, Yeah. In K. Lynard (Ed.), Gifts: *Mothers Reflect on How Children with Down Syndrome Enrich Their Lives* (pp. 25-29). Bethesda, MD: Woodbine House at p 28.

[24] Choosing Down Syndrome at p 46.

[25] Perfectly Human at p 80.

[26] Reimer, J. (2007). On His Thirteenth Birthday. In K. Lynard (Ed.), *Gifts: Mothers Reflect on How Children with Down Syndrome Enrich Their Lives* (pp. 16-20). Bethesda, MD: Woodbine House at p 19.