DEADLY DISCRIMINATION IN ALBERTA

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Introduction

“Your baby won’t be able to feed itself or dress itself. It will be a burden on society.”

“You should abort and try again.”

“Your life will be over.”

Expectant parents in Alberta hear statements like these from medical professionals upon receiving news that their unborn child has been diagnosed with Down syndrome.[i] These parents sometimes regret undergoing prenatal testing because of how they are subsequently treated by staff in the medical system. This paper examines current policies around prenatal testing and offers recommendations to improve informed consent and help make women’s pregnancies a more positive experience.

When parents make an informed decision to welcome a child with Down syndrome or any other disability into their family, this is a decision that should be supported by the Government of Alberta, the medical community, and all Albertans.

Background

Congenital Conditions

Congenital conditions are those which are present before or at the time of birth. Examples include hereditary diseases such as Tay-Sachs disease, cystic fibrosis, and sickle cell disease. They can also include structural issues such as heart or neural tube defects. Chromosome anomalies such as trisomy 21 (Down syndrome), trisomy 13 (Patau syndrome), or trisomy 18 (Edwards syndrome) are also congenital conditions.[1]

Some congenital conditions impair a person intellectually, while other conditions are physical. Some conditions are permanent. Others can be treated either in-utero or after birth; for example, surgery can fix a cleft palate or certain heart problems.[2] Congenital conditions can have anywhere from a minor to a major effect on a person's quality or length of life, dependent on the condition and other various factors. It is possible to have a disability, such as blindness or an intellectual impairment, and still be in a state of perfect health.

The most common chromosome anomaly is Down syndrome. There is no connection to ethnicity nor any known behavioural or environmental factors contributing to Down syndrome except that

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[i] While outside of North America, some countries still refer to Down syndrome as ‘Down’s syndrome,’ the Canadian Down Syndrome Society (CDSS) asserts it is ‘Down syndrome’ because it is named after John Langdon Down, who did not himself have Down syndrome. See CDSS, “About Down Syndrome,” accessed January 4, 2025, at https://cdss.ca/resources/general-information/.

instances increase with a mother's age. It occurs at the formation of an egg or sperm—or rarely, after fertilization as the embryo grows—when cells divide in a way that splits chromosomes abnormally. About 95% of people with Down syndrome have "complete" Down syndrome, which means each cell in the person's body has three copies of chromosome 21. About 3% of people with Down syndrome have an extra part or whole extra chromosome 21, but it is attached to another chromosome rather than being separate ("translocation" Down syndrome). About 2% of people with Down syndrome have some cells with three copies of chromosome 21 but other cells with two copies ("mosaic" Down syndrome). People with mosaic Down syndrome may have fewer characteristics associated with Down syndrome, dependent on which cells have three copies of the chromosome.[3] While people with Down syndrome often share common physical features with other people with Down syndrome, they still resemble family members and have their own unique personalities.[4]

Approximately 1 in 800 live-born babies in Canada have Down syndrome, and an estimated 45,000 Canadians live with the condition.[5] The number of live births in Canada in 2023 was reported as 351,477, meaning around 439 of those babies would have Down syndrome.[6]

Ableism in Society

On a societal level, Canadians are united in the belief that discrimination is wrong, whether it is discrimination against women, people of colour, the LGBTQAI2S+ community, or people with disabilities. Unfortunately, the history of discrimination against people with disabilities is ugly, and Alberta's history is even darker than the histories of many comparable jurisdictions.

Alberta was the first jurisdiction in Canada to pass a sterilization law with the *Sexual Sterilization Act* on March 21, 1928. It established the four-member Alberta Eugenics Board, which was empowered to direct physicians to sterilize individuals discharged from mental institutions. At the board's instruction, more than 2,800 sterilizations were performed.[7] Alberta historian Alvin Finkel noted that during this time, some boys with Down syndrome even had a testicle removed so that a researcher could study the potential causes of the condition.[8] British Columbia then followed Alberta's lead and also passed a formal sterilization law in 1933.[9]

Alberta was not only the first, but the most zealous. W. Mikkel Dack, who studied history at the University of Calgary, writes, "During the late 1930s, a time when the great majority of regional governments were either decommissioning or disregarding their sterilization laws due to a lack of funding, the discrediting of scientific racism and an increase in public protest, Alberta expanded its own legislation."[10]

Originally, some form of consent was required on the part of the person being sterilized, but then Alberta's Minister of Health, Dr. Wallace Cross, and the Director of Mental Health for Alberta, Dr. Charles A. Baragar, advocated for consent to not be required. In March 1937, an amendment was passed to this effect.[11] Another amendment was passed in 1942 that expanded eligibility.[12] Alberta's sterilization law remained on the books until 1972.[13]

Some researchers have suggested that Alberta's past eugenics policies were primarily motivated by a desire to improve the province's economic situation. However, in studying numerous statements and reports from politicians, mental health professionals, and journalists at the time, Dack is convinced otherwise. For examples, he quotes an article in the medical journal *Mental Health* that suggested Albertans should "give more attention to raising and safe-guarding the purity of the race," and an editorial in *Medicine Hat News* on February 24, 1928, stating it is the "quality of humanity that is in question."[14] Dack asserts that instead of being about money, the arguments favouring Alberta's eugenics policies closely resembled "the Nazi racial interpretation of *Volk* and the burden of the *Untermensch* (sub-human)."[15]

Historically, throughout Canada, many children with disabilities like Down syndrome were institutionalized at a young age and remained so for their entire lives. In Alberta, in 1923, the Provincial Training School (later the Michener Centre) for "mental defectives" was opened in Red Deer, and at one point, the complex housed more than 2,300 people. Alberta also had mental institutions in Ponoka and in Edmonton's neighbourhood of Oliver. Research and interviews with former residents, their family members, and former staff members have found that abuse and violence were common at institutions like these. In the 1970s and 1980s, organizations like the Alberta Association for Community Living advocated for a transition away from large institutions to a community-living model for people with disabilities.[16]

Living with Down syndrome

People with Down syndrome and other disabilities frequently lead worthwhile lives and contribute positively to the families in which they grow up and to society at large.

The life expectancy of those with Down syndrome has increased dramatically over the past several decades. In 1960, a person with Down syndrome would live to be about 10 years old,[17] but today, the average expectancy is 60. One reason for this improvement is that the heart defect suffered by many people with Down syndrome can now be diagnosed and treated. Another is that Canadians with disabilities seem to generally fare much better living with family and in community rather than in large institutions, an arrangement that has become more common in recent decades.[18]

Despite the low expectations sometimes placed on them, adults with Down syndrome often exercise significant independence and live on their own or with a roommate. Some get married, sometimes to another person with Down syndrome and sometimes to a person without.[19] Throughout the world, people with Down syndrome have advocated for themselves and others. They have given speeches and written autobiographies.[ii]

[ii] Here are just a few examples: Frank Stephens (Global Down Syndrome Foundation), Matthew Schwab (Matthew Schwab Speaks), Paul Sawka (Canadian Down Syndrome Society), and Charlotte Helene Fine.

Research into both families of children without disabilities and of children with disabilities has found a comparable level of variation among families with respect to well-being, overall adjustment, family functioning, and marital satisfaction.[20]

In the United States, Harvard-trained physician and researcher Brian Skotko conducted a national survey of people with Down syndrome who were 12 and over. The overwhelming majority responded that they were living happy lives and loved their families (99%). Among the small percentage of people who reported they were sad, most were young adults in or just out of high school, which is often an uncomfortable time for teenagers without Down syndrome, as well, and might simply mean that they experience many of the same struggles as their peers.[21]

Skotko's survey of siblings of children with Down syndrome found that more than 96% of brothers and sisters reported affection toward their sibling, less than 10% felt embarrassed, and less than 5% expressed a desire to trade their sibling in for another without Down syndrome. Among older siblings, 88% felt that they were better people because of their sibling, and more than 90% planned to remain involved in their sibling's life as they became adults.[22]

Dr. Chris Kaposy, a Canadian bioethics professor, writes:

> There is substantial empirical evidence documenting that people with Down syndrome and other disabilities tend to positively assess their own well-being. There is also substantial empirical evidence showing that families that include a person with Down syndrome tend to function well. This data involves both subjective and objective measures. … I see no reason to question the findings myself. … The burden of proof lies on those who would overrule the subjective reports. The philosophers who think that cognitive disability necessarily leads to diminished well-being have not met this burden.[23]

Prenatal Testing

Each year in Canada, approximately 450,000 women become pregnant, with 70% participating in prenatal screening for Down syndrome.[24] Prenatal testing for Down syndrome first started in the late 1950s but did not become routine in developed countries until the 1990s or early 2000s.[25]

In Alberta, the rate of fetuses conceived with Down syndrome, trisomy 13, and trisomy 18 is increasing and strongly correlated with increasing maternal age. In 1980, approximately 5% of mothers were 35 years of age or over when their baby was born, whereas in 2021, one quarter of women who gave birth were in this age category.[26] Still, around half of the babies born with Down syndrome are born to mothers under the age of 35, because more babies are born to women under 35.[27]

According to the Public Health Agency of Canada: "Despite the trend in delayed childbearing and advanced maternal age at delivery in the last several decades, rates of Down syndrome in Canada have not increased proportionately. This is due to increased use of prenatal diagnostic procedures followed by terminations of Down syndrome pregnancies."[28]

Types and Methods

There are two types of prenatal tests: screening tests and diagnostic tests. A screening test shows the chance that a developing baby has a chromosomal condition, whereas a diagnostic test is considered conclusive but is more invasive than a screening test.[29]

Screening tests include a nuchal translucency ultrasound or a blood (or maternal serum) test. These can also be done in combination. The ultrasound is usually carried out between 11 and 13 weeks of pregnancy and measures an area at the back of the baby's neck. An increase in the thickness can be an early sign of certain genetic conditions such as Down syndrome. Blood tests check the level of substances that are related to certain birth defects and genetic conditions.[30] Among the women who undergo screening, 4% have a positive result indicating a higher likelihood of an abnormality.[31]

Non-invasive prenatal testing (NIPT), also known as cell-free fetal DNA testing or cfDNA, is a recently developed screening method that involves drawing a blood sample from the mother, which contains DNA from the mother as well as DNA from the fetus.[32] In the 1990s, researchers found fetal cells circulating in a mother's blood, and 10 years later, researchers showed that an analysis of these cells could detect trisomy 21. NIPT became available in 2011 and within 10 years was available in more than 60 countries.[33]

NIPT is primarily used to screen for trisomies 13, 18, and 21, as well as sex chromosome aneuploidies like Turner syndrome, Klinefelter syndrome, and triple X syndrome, but analyzing DNA can provide information far beyond the likelihood of abnormalities.[34] In a 2022 study, Canadian medial professionals note that its ongoing technological development may soon enable parents to learn extensive information about a fetus, such as whether it will have an increased genetic predisposition to certain diseases or its eye colour.[35]

Indeed, the company BillionToOne Inc., based out of California, is currently (as of February 2025) advertising a "BabyPeek" prenatal test, which at 10 weeks into pregnancy will provide parents with a report on probabilities on 12 traits: eye colour, red hair, curly hair, light or dark hair, hair thickness, freckles, cilantro aversion, ability to detect bitterness, ability to smell asparagus-related odor, sweet tooth or not, preference for sweet versus salty foods, and timing of teething.[36] While most expectant parents would likely obtain this information just for fun, researchers have noted that some people have admitted they would terminate wanted pregnancies if the fetus is considered medically normal but yet does not possess a desired trait. For example, if the fetus is not a certain sex or if a deaf couple did not want a baby who could hear.[37]

Diagnostic tests, which are considered conclusive, include chorionic villus sampling (CVS) and amniocentesis.

CVS is typically performed in the late first trimester. Chorionic villus cells are found in the placenta and carry the same genetic material as fetal cells. A sample of these cells is either collected by putting a thin flexible tube (catheter) through the vagina and cervix into the placenta or by putting a long, thin needle through the belly into the placenta, using ultrasound to guide the catheter or needle into the correct position. The sample is then examined for chromosome anomalies, such as Down syndrome.[38]

Amniocentesis is carried out in the second trimester, between weeks 15 and 20, and involves putting a needle through the belly into the uterus to withdraw about 2 tablespoons of amniotic fluid.[39]

Risks

Amniocentesis is associated with a 0.5 to 1% risk of miscarriage.[40] Approximately 10,000 pregnant Canadian women undergo amniocentesis each year, which will confirm around 315 cases of Down syndrome as well as result in the loss of 70 babies without Down syndrome due to the risks associated with the procedure.[41] CVS, while it can be performed earlier in a pregnancy than amniocentesis, has a higher risk of miscarriage, occurring in about 1 of every 100 procedures (1%).[42]

There is also a high risk of initial screening results being misunderstood. Research has shown that people tend to misinterpret probabilities. One study presented information to pregnant women, obstetricians, and midwives about the correlation between a positive screening result and a baby with Down syndrome. The scenario they were presented is as follows:

> Approximately 1% of babies have Down syndrome. If the baby has Down syndrome, there is a 90% chance that a blood screening test will be positive. If the baby does not have Down syndrome, there is still a 1% chance that the result will be positive. If a pregnant woman has been tested and the result is positive, what is the chance the baby actually has Down syndrome?

The researchers also expressed the scenario as a frequency instead of a percentage:

> Approximately 100 babies out of 10,000 have Down syndrome. Of these 100 babies, 90 will have a positive screening test result. Of the remaining 9900 unaffected babies, 99 will still have a positive result. How many pregnant women who have a positive result to the screening test actually have a baby with Down syndrome?

The correct mathematical answer to the scenarios above is that 47.6% of pregnant women who initially receive a positive screening result would actually have a baby with Down syndrome. Most respondents (86%) incorrectly judged the probability, with respondents answering that a genetic anomaly was either “almost certainly present” or “almost certainly absent.” If respondents thought the anomaly was almost certainly present, it is because they had relied on the sensitivity of the tests, whereas if they thought the anomaly was absent, this was due to them relying only on the base rate of one per cent.[43]

In Quebec, it was found that in 2015, about 4.5% of pregnant women who participated in prenatal screening received a positive result. Most of the results were false positives, which researchers said led to "a high number of unnecessary amniocenteses."[44]

The choices made by pregnant women who incorrectly understand the limitations and risks associated with prenatal screening and testing may differ markedly from the ones they would make if the information were presented in a clear and robust way

Current Policies

In 2007, clinical practice guidelines in Canada were updated to recommend that all pregnant women be offered prenatal screening. The guidelines previously recommended screening only for women ages 35 and up, when the risk of losing a fetus as a complication of amniocentesis is equal to the chance of giving birth to a child with Down syndrome.[45] In other words, the guidelines suggest that unknowingly giving birth to a child with Down syndrome would be worse than miscarrying a baby without Down syndrome.

Alberta Health Services (AHS) currently offers screening tests in the first and second trimesters, as well as integrated screening tests that combine the results from both first- and second-trimester tests. If a screening test sees a higher chance of a fetus having Down syndrome, pregnant women are offered diagnostic testing. However, if a pregnant woman intends to have a conclusive diagnostic test regardless of a screening test's results, she can skip screening entirely and undergo CVS or amniocentesis.[46]

NIPT was introduced in Canada in 2013. Currently, AHS does not typically fund NIPT, but Albertans can pay for it out of pocket, or it may be insured through private health plans.[47] It may be considered expensive, but not prohibitively so for many families. The Harmony test is currently advertised online at $349.[48] There are some conditions under which healthcare providers in Alberta may request the government to fund NIPT for a patient through AHS's Genetic Resource Centre.[49] Those conditions include a higher likelihood of the fetus having a chromosomal condition in addition to the mother having a health complication such as HIV, hepatitis, or a shortened cervix, all of which make an invasive diagnostic procedure even riskier.[50]

In 2014, Alberta participated in a $10-million national study titled PEGASUS (PErsonalized Genomics for prenatal Aneuploidy Screening USing maternal blood), recruiting around 900 women in Calgary.[51] PEGASUS researchers were interested in analysing whether NIPT should replace invasive diagnostic tests within the public healthcare system, given that NIPT is often touted as being extremely accurate and 70 babies without Down syndrome are lost each year in Canada due to procedural complications.[52] In 2017, they concluded that based on the NIPT performance data, invasive diagnostic testing is still required "to confirm the presence of a chromosomal abnormality prior to making irreversible decisions relative to the pregnancy outcome."[53]

In other words, NIPT is increasingly being viewed by medical practitioners as a preferred screening method that is more accurate than a nuchal translucency ultrasound or blood test, but it is not considered accurate enough to replace CVS or amniocentesis to confirm the presence of Down syndrome before an abortion is carried out.

For clarity purposes, it should be noted that not all ultrasounds during pregnancy are to screen for birth defects or Down syndrome. Ultrasounds can provide medical information such as the age, size, and position of the fetus, placenta, or amniotic fluid, which is useful for a variety of purposes.[54]

Its Purpose

While the individual motivations of parents may vary, at a systemic level, prenatal testing is about preventing the births of people with disabilities like Down syndrome by identifying and aborting them. One Canadian physician shared that prenatal screening has been colloquially referred to by physicians at medical conferences as "seek and destroy."[55] As confirmed by the Society of Obstetricians and Gynaecologists of Canada in 2024: "Over the last few decades, most high-resource countries have implemented prenatal genetic screening programs with the objective to detect fetal anomalies and provide reproductive options to pregnant persons."[56]

On the one hand, it is obvious that abortion is the purpose of prenatal screening. On the other hand, a person could be excused for not realizing this, given how the medical community obfuscates its purpose. Dr. Nancy Press writes, "Avoiding honest discussion of the meaning and purpose of prenatal screening exists not only at the level of patient-clinician interaction but in the 'hard' and 'soft' scientific literature as well."[57]

Dr. Marsha Saxton, a disabilities study scholar, writes, "Women are increasingly pressured to use prenatal diagnostic testing under a cultural imperative that undergoing these tests is the 'responsible thing to do,' and that "the ostensible justification is 'reassurance that the baby is fine.'"[58]

But, Dr. Saxton asserts, the underlying communication to mothers is that bringing babies with disabilities into the world is wrong, and she quotes a mother whose fetus was found to have a neural tube defect: "It seemed as though every time I turned around another physician was asking me whether or not anyone had discussed my 'options' with me. 'Options' has clearly become a euphemism for abortion."[59]

Is it Ableist?

Some medical professionals and thinkers have expressed concerns about prenatal testing being inherently discriminatory. This includes people who self-identify as "ardently pro-choice" and do not oppose abortion generally, but who have urged prospective parents to “examine the meaning” of prenatal testing, selective abortion, and society’s cumulative actions.[60]

Firstly, when terminating an otherwise wanted pregnancy on account of a disability, there may be a misguided assumption about what it means to be a parent. Bioethics scholars Erik Parens and Adrienne Asch write:

> When prospective parents select against a fetus because of predicted disability, they are making an unfortunate, often misinformed decision that a disabled child will not fulfill what most people seek in child rearing, namely “to give ourselves to a new being who starts out with the best we can give, and who will enrich us, gladden others, contribute to the world, and make us proud.” […]
>
> Do not disparage the lives of existing and future disabled people by trying to screen for and prevent the birth of babies with their characteristics. […] As with discrimination more generally, with prenatal diagnosis, a single trait stands in for the whole, the trait obliterates the whole. With both discrimination and prenatal diagnosis, nobody finds out about the rest. The tests send the message that there’s no need to find out about the rest.[61]

Leo Kittay, who grew up with a severely disabled sister, writes:

> No human child is fit for survival without the help of elders. To start drawing the line about how much help they should need is extremely problematic. … What kind of message does aborting the [disabled] send to would-be siblings? … My parents wouldn’t just love any child they might have, they love me because I possess the desirable properties or characteristics that make me who I am. What I am trying to say is that the family starts to seem more like a club, and less like a family. In a club the members are selected based on one characteristic or another. This leads one to believe that if, for some reason, that characteristic is no longer attributable to the individual, or if anyone in the club comes to believe that this characteristic never applied, the membership in the group and the ‘love’ that results can vanish.[62]

Asch warns prospective parents that children and family members can also become disabled later in life:

> [It is dangerous to assume] that only the twists of detectable impairments are problems, that anything else is acceptable, but that disability is different, worse, unacceptable. It assumes that the attitude toward avoiding a detectable disability in a once-wanted child will not carry over into the attitude of rejecting or not appreciating the child who acquires a disability at two or twelve, the partner at twenty, the friend at forty, and parents when they are in their eighties. … Where do we first learn justice, sharing, and cooperation, but in the family?[63]

Secondly, Canadian researchers have expressed concerns that individual terminations of pregnancies based on abilities will collectively add up and result in harm to living people with disabilities:

> Trivialisation of pregnancy termination might lead to loss of diversity in society, which in turn, might exacerbate discriminatory attitudes towards those individuals who present traits that are different from what is accepted in a eugenic society, a society looking for 'perfect babies.'[64]

From an economic perspective, it may be assumed that people with Down syndrome will use more government-funded programs, like the public healthcare system, than would people without a congenital condition. This may be part of the government's motivation to fund and encourage the use of prenatal screening programs. In response, arguments have been made that people with disabilities do not present the economic burden some people expect them to but also that even if they did, this is not justification to pressure their mothers to abort them.

Dr. Saxton writes:

> Of course, cost-benefit analysis is not woman-centered, yet women can be directly pressured or subtly intimidated by [the cost-benefit argument]. It may be difficult for some to resist the argument that it is their duty to 'save scarce health care dollars,' by eliminating the expense of disabled children. But those who resist these arguments believe the value of a child's life cannot be measured in dollars. It is notable that families with disabled children who are familiar with the actual impact of the disabilities tend not to seek the tests for subsequent children. The bottom line is that the cost-benefit argument disintegrates when the outlay of funds required to provide services for disabled persons is measured against the enormous resources expended to test for a few rare genetic disorders.[65]

Canadians routinely pride themselves on having a healthcare system that is accessible to everyone. Furthermore, many Canadian residents without disabilities consume more taxpayer-funded resources than they pay for. According to a 2019 article in the *Financial Post*:

> On average, two of every five Canadian households do not pay anything towards federally and provincially funded expenses such as health care, education, community and social services, national defence, public safety and even the good old Canada Revenue Agency. One household of every five pays much more than 70 per cent of all of those costs.[66]

Dr. Kaposy also writes on this issue:

> Economic competitiveness is only one value among many. It is not the whole of society. And the societies that prioritize this one value over all others may not be very humanitarian. Aside from participation in the competitive market, a child with a disability like Down syndrome will be born into a family, into a community, into cultures, into a nation-state that is defined by laws rather than exclusively by market forces. He or she will become

> involved in social practices and relationships that are not defined by the market—relations of love, friendship, citizenship, and many others. Even if people with Down syndrome do not typically become optimal participants in the market economy (though many do), they and others with disabilities can make small and large contributions to social life within these other meaningful areas of human association.

Society has arguably come a long way in terms of recognizing the equality of all persons regardless of race, gender, or sexual orientation. But it still permits disability to be approached in a discriminatory manner and fails to properly recognize the inherent worth of all people with disabilities.

Consider that in the 1990s, scientist James Watson—who along with three other scientists is credited with discovering DNA—argued that if a gene is discovered that determines whether someone will be homosexual, women should be allowed to abort fetuses on account of them being homosexual. His comment provoked a backlash from both anti-abortion activists and the LGBTQAI2S+ community, and he has since been stripped of honorary titles.[67]

In contrast, within the last decade, a French organization produced a short video titled “Dear Future Mom” with the simple premise “People with Down syndrome can live a happy life.” In 2016, France’s Council of State, a branch of the government, affirmed a ban on the video by the French Broadcasting Channel, claiming it might influence women to continue with a pregnancy where the fetus is diagnosed with Down syndrome.[68] The video is reassuring in tone and said nothing opposing abortion generally. By banning it, the government clearly showed a discriminatory bias against people with Down syndrome.

Informed Consent and Choice

Canadians across the political spectrum typically agree about the moral importance of informed consent in medical affairs, as a matter of individual rights and autonomy. However, the relationship between prenatal testing and informed consent in Canada is questionable. As noted previously, the medical community is often unclear to its patients about the purpose of prenatal testing.

Written by researchers in Saskatchewan, a January 2024 article in the *Journal of Obstetrics and Gynaecology Canada* states:

> The narratives of several participants illustrated that they were screened without their explicit choice. These participants relayed descriptions of being sent for bloodwork without being told what it was for:
>
> “I went for the triple screen…it was the first time that I’d ever done that. I didn’t even know what I was going for... the lab tech just said, ‘you’re here for the triple screen’. I said ‘I don’t know what that’s for.’”[69]

The researchers also found:

> Prejudice towards Down syndrome (and other fetal anomalies) was also present in care providers' counselling, threatening informed choices about screening, testing, or termination. For example, some care providers assumed that patients would choose to terminate a pregnancy when a Down syndrome determination was made:
>
> "(The) doctor blurts out on the phone, 'Um, your son…has Down Syndrome'… the next thing he said was 'when can I schedule your termination?'"[70]

The researchers concluded:

> Analyses of the information provided to individuals considering prenatal screening or elective termination for Down syndrome find that it is typically medical and negative and that parents report it does not meet their needs.[71]

The author of this report spoke to two mothers of children with Down syndrome who were pregnant in the Edmonton region, one in 2013-14, the other in 2023. Though ten years apart, their experiences were remarkably similar. Phrases they vividly recall being told by medical practitioners include:

"Your baby won't be able to feed itself or dress itself. It will be a burden on society."

"Your life will be over."

"You should abort and try again."

"Don't worry about it. People abort for a cleft lip. It's not a big deal."

One of these two mothers recounted a genetic counsellor even incorrectly told her that trisomy 21 could be lethal to the mother carrying the fetus.

One of their children underwent heart surgery shortly after birth. The mother recounted that another parent with a newborn child at the Stollery Hospital in Edmonton proclaimed to her that her own baby had come back "normal" during prenatal testing, giving off the impression that she felt the need to explain herself. While this parent's internal motivations are unknown, literature indicates that historically, society has placed shame or blame on parents for having a child with a disability, and this parent may have been dealing with a sense of shame or embarrassment.[72]

The anecdotes above are not necessarily the experience of every mother in Alberta, but they serve as important indications that improvements can be made to how parents receive information about their babies and to how they are supported while making irreversible decisions.

Stories of expectant parents being pressured to undergo prenatal screening and then to terminate the pregnancies of children diagnosed with disabilities are not limited to Alberta but are found worldwide, with examples easy to find in the mainstream media.[73]

Academic studies have confirmed the issue. For example, in 2021, a survey of 300 families in Australia found that 49 per cent of women felt pressured to terminate their pregnancies following a prenatal diagnosis of Down syndrome.[74] In the Netherlands, mothers of children with Down syndrome born between 2010-2016 reported an emphasis on the option of terminating pregnancy, while none felt pressured to continue the pregnancy.[75] According to researchers, pressures to test, terminate, or both "can range from explicit coercion on the part of healthcare providers to subtle influences of prevailing social norms."[76]

An anonymous survey of primary care physicians in the United States, published in 2005, revealed that:

- 63% self-reported that they tried to be as unbiased as possible when delivering a prenatal diagnosis;
- 13% reported that they emphasize negative aspects of Down syndrome so that parents would favor a termination;
- 10% actively urged parents to terminate;
- 10% emphasized the positive aspects of Down syndrome so that parents would favor continuation; and
- 4% actively urged parents to continue the pregnancy.[77]

In summary, almost one in four surveyed physicians admit to showing bias towards termination.[78]

Professors Philip M. Ferguson, Alan Gartner, and Dorothy K. Lipsky conclude, "What we are left with is all too often the opposite of choice, where the prospective parents feel challenged if they select any other action but abortion."[79]

Risks

When a woman decides to terminate her pregnancy, it must be an informed decision. While not the focus of this paper, induced abortions do carry risks. In a meta-analysis of 37 studies exploring the relationship between a history of abortion and adverse pregnancy outcomes, researchers concluded that abortion significantly increases risks of low birth weight and preterm births for later pregnancies.[80] A Canadian study published in 2013 showed the same.[81] A current theory as to why is that mechanical trauma to the cervix causes "cervical insufficiency."[82] Researchers indicate that complication rates may be higher if the subsequent pregnancy is earlier rather than later, but more data is needed to ascertain this.[83]

Premature or low birth weight deliveries in turn increase the chances for disabilities in those babies, including but not limited to cerebral palsy, intellectual disability, and "disorders of psychological development, behavior and emotion.[84] If Down syndrome, which is an intellectual impairment, is the reason for an induced abortion, this is particularly relevant information. Women who want a child but who are pressured to "abort and try again" in hopes of a different outcome (a child without a disability) may not find it as easy as they were encouraged to believe.

According to a 2013 article in the *Journal of Obstetrics and Gynaecology Canada*:

> The rate of preterm birth has been increasing, and in 2006 in Canada it was estimated to be approximately 8.1%. An association between induced abortion and prematurity in subsequent pregnancy has been demonstrated in several studies. This relationship is very relevant for Canada because of the high number of abortions performed annually. In 2005, there were 96,815 abortions performed in Canada, with 342,176 births in that same year.[85]

Another risk, one of relevance to women who are advised to abort a fetus with a disability on compassionate grounds, is the chance that the child will be born alive during an induced abortion. In a study of 13,777 second-trimester abortions carried out in Quebec between 1989 and 2021, for which fetal anomaly was the reason almost half the time, 11.2% of abortions resulted in a live birth. One-quarter of the babies born alive were admitted into neonatal intensive care units. The researchers do not know for how many hours the babies survived or whether those not admitted into intensive care received any type of palliative care at all. The researchers "could not assess the possible psychological impact on staff and parents, or potential difficulties experienced by the newborn."[86]

Informing Policy

Research has shown that government and medical community guidelines and policies related to prenatal testing do, ultimately, have an impact on whether people with Down syndrome are born.

Denmark was reportedly the first country in the world to offer prenatal screening for Down syndrome to all pregnant women, beginning in 2004. Researchers examined the correlations between national screening guidelines and the rates of prenatal diagnoses and live births of babies with Down syndrome between 1973 and 2016. They found that the national guideline to screen all pregnant women did have an impact on the "outcomes" of prenatal screening. While the number of babies born with Down syndrome was stable in Denmark until 2004, the introduction of combined screening for all pregnant women resulted in the number of babies born with Down syndrome being halved.[87]

When discussing policy, it is important to distinguish between actions designed to prevent disability and terminating a pregnancy due to disability. Consider, for example, the way that pregnant women are encouraged to take folic acid supplements to prevent the fetus from developing neural tube defects. It could be argued that encouraging termination of Down syndrome fetuses is no different in nature from encouraging pregnant women to take folic acid. Both actions acknowledge that disability is not something sought after and might be considered ableist. If disability is to be embraced and accepted, why is there a need for folic acid? Would it not be hypocritical to both take it and decry the termination of Down syndrome fetuses? However, folic acid prevents a disability. Termination, despite how the rhetoric sometimes goes, does not prevent Down syndrome. It removes the child affected by it from society.

Asch writes:

> ‘Don’t participate at all if you will have a disability’ differs markedly from ‘Let’s do the best we can to make sure that all our future children avoid disability, but we will expect that people are born with and acquire disabilities, and we will include everyone no matter the disability.’[88]

Susan Wendell, who was Associate Professor of Women’s Studies at Simon Fraser University in British Columbia, acknowledges that disabilities can indeed be burdensome and are best avoided, but she argues that it does not follow that termination is the right response when a fetus likely has a disability:

> I would be terribly sorry to learn that a friend’s fetus was very likely to be born with [the disability myalgic encephalomyelitis], but I would not urge her to abort it. In other words, many people with disabilities, while we understand quite well the personal burdens of disability, are not willing to make the judgment that lives like ours are not worth living. Every life has burdens, some of them far worse than disability.[89]

Other Jurisdictions

Policymakers and non-profit organizations can often benefit from looking beyond our borders at what other governments and organizations are doing. Below is a sampling of initiatives and practices in other countries that support people living with disabilities.

Australia

Down Syndrome New South Wales started “The Congratulations Initiative,” which is aimed at encouraging medical professionals to say “congratulations” instead of “sorry” when delivering a diagnosis of Down syndrome to parents. The organization provides up-to-date information about Down syndrome in their Medical Professionals Packs and links their organization as a key support partner.[90]

Ireland

In February 2024, Ireland’s Minister for Further and Higher Education, Research, Innovation and Science announced the introduction of micro-credentials and higher education courses for students with an intellectual disability. New courses commenced at 10 colleges across the country in the 2024-25 school year.[91] A micro-credential certifies that someone has knowledge in a particular area, often a skill of interest to potential employers.

The Netherlands

In the Netherlands, the government emphasizes on its website that prenatal screening is optional:

> As a pregnant woman living in the Netherlands, you have the option of having your child tested before birth. In this way, you can opt for tests that screen for Down’s, Edwards’ and Patau’s syndromes. It is worth noting that not all pregnant women opt for screening tests, but all will be offered them.[92]

Researchers have noted that fewer pregnant women in the Netherlands opt in to prenatal testing than women in neighbouring countries such as Denmark, and they suggest:

> The relatively low national screening uptake might be that we, in the Netherlands, tend to take a more positive view of people with Down syndrome […]. It might also be due to the carefully considered way in which screening is offered here, and to the associated counselling process.[93]

The "right not to know" principle written into law in the Netherlands gives patients explicit ownership over what information is collected and delivered to them.[94] The country's *Population Screening Act* was introduced in 1996 and "provides protection against unnecessary or harmful screening programmes."[95] The country's Ministry of Health, Welfare and Sport publishes detailed information about prenatal screening in multiple languages online.[96] In addition, the government states that before pregnant women make their decision, "they will be able to discuss [prenatal testing] at length with their midwife or gynaecologist.[97]

United Kingdom

Citizens and organizations in the United Kingdom (UK), including Down's Syndrome Research Foundation UK, the disability advocacy group *Don't Screen Us Out*, and the National Down Syndrome Policy Group, strongly support a proposed change to the UK's *Abortion Act* that would protect fetuses diagnosed with Down syndrome the same as fetuses without.[98] The *Abortion Act* currently allows for a fetus diagnosed with Down syndrome to be aborted up to 40 weeks gestation, while most fetuses are protected by law after 24 weeks.[99]

In spring 2024, an amendment to this effect was sponsored by Members of Parliament (MPs) across the political spectrum, including Conservative, Labour, Liberal Democrat, Scottish National Party, Workers Party of Britain, and Democratic Unionist Party MPs, but the House of Commons ultimately never voted on it.[100]

In addition, the Down's Syndrome Association in the UK has several active campaigns to support the equality of people with Down syndrome, including Tell It Right®. This campaign includes the facilitation of focus groups to help ensure that the lived experience of individuals who have Down syndrome and their families are reflected in the written resources available to pregnant women. It also provides training to healthcare professionals on non-directive advising techniques that enable women to make informed decisions about what is right for themselves.[101]

United States

Pennsylvania

About ten years ago, Pennsylvania passed the *Down Syndrome Prenatal Education Act*, also referred to as Chloe's Law, to ensure that the information made available to parents is up-to-date, evidence-based, and reviewed by medical experts and disability support organizations. Chloe Kondrich's father worked to pass the law because he believed there was little information on the positive aspects of raising a child with Down syndrome.[102] Chloe has spoken at national and international events with a message of "Embrace, Don't Erase."[103]

Massachusetts

At Brandeis University in Massachusetts, a program was initiated that had genetic counselling students interact informally—outside of a medical environment—with people living with disabilities. The Master's in Genetic Counseling program "places a strong emphasis on disability awareness and the lived experience of individuals and families with a disability or genetic condition."[104]

A researcher interviewed Brandeis University students before and after they met with people with disabilities. The students revealed a significant shift in thinking. Students reported being struck by how little interaction with "real people with disabilities" they had experienced before the program. A student said:

> I think it's ridiculous … all these professionals, talking and talking, but not with people with disabilities; this elite group makes decisions, but not involving anybody else. We don't want to admit this is a form of eugenics; don't want to be associated with that word… I've brought it up before but people in my field don't really want to talk about it.[105]

Students moved from viewing disability as a personal tragedy to viewing it as an experience informed by societal discrimination. Another student said: "In talking with the other students, we all had these sort of mini-revelations about what disability is. I don't know if I would have ever done that if we hadn't been required to. Everybody had a great experience—I mean, incredible."[106]

Recommendations

Alberta policymakers have an opportunity to enhance the experience of pregnant women, improve informed consent, and affirm the worth of people with disabilities.

The six recommendations below are key areas where the Government of Alberta and the medical community should consult with stakeholders and act to support women and families. Stakeholders would include but are not limited to: Edmonton Down Syndrome Society, Ups and Downs Calgary Down Syndrome Association, Down Syndrome Foundation of Canada, and the Canadian Down Syndrome Society.[107]

1) Emphasize that prenatal testing is optional and improve informed consent by providing detailed information

Pregnant women in Alberta should clearly understand the purpose of prenatal testing as well as the limitations and associated risks of any procedure.

The Government of Alberta and AHS should prepare—in collaboration with disability support organizations—standardized content in multiple languages to proactively communicate detailed and easy-to-understand information about prenatal testing and subsequent options. Such resources would enhance informed consent without slowing down the operations of the healthcare system. As researchers have noted, “Often patients have been referred by physicians and do not understand that prenatal testing is an option that, in light of their values, beliefs, and needs, they may not want to use.”[108]

A mother in Alberta who was pregnant over 30 years ago is now grateful in hindsight that she did not undergo testing, as testing at the time was not standard. She recounts having a “wonderful doctor” who simply advised her after her baby with Down syndrome was born to, “take her home and love her!” She states:

> [Prenatal screening] is a personal choice of course and for some that might be good, but personally, I would have missed the beauty and joy I experienced during my pregnancy of not knowing anything about this child of ours until she was born. We and the world around her would have missed out on the blessing and joy she has brought all these years and years to come. I… we… could love her from the moment we knew we were pregnant and enjoy the journey.[109]

A different mother in Alberta who gave birth for the first time in 2024 told this author:

> I was annoyed that my doctor and the information I read wasn’t clear about why I would benefit from the testing. I would love it if materials explained that the screen is so that the parents can either a) choose to abort or b) spend their time researching and preparing to care for a baby with special needs… rather than just saying vague nonsense about telling me my options after the test results come back.[110]

While some information on Alberta’s prenatal testing programs is available online and has been cited at length earlier in this paper, it could be more transparent and user-friendly. Also, up-to-date printed materials on prenatal testing should be handed to patients early in their pregnancies to be read and reviewed in a low-pressure environment. Printed materials need not be comprehensive but should direct those who are interested to more detailed information.

2) Train medical practitioners engaged in prenatal testing to use neutral or positive language

Medical practitioners should be trained and encouraged to use neutral or positive language, and not to fear monger, when meeting with families. For example, rather than prefacing a diagnosis with, “I’m so sorry,” they could say, “The test shows…”[111]

Laura Howard, a mother of a child with Down syndrome, says, “People’s reactions, people’s tones, people’s words have such a massive impact.”[112] Medical staff providing prenatal tests could use language like ‘probability’ or ‘chance’, not the term ‘risk’. They could talk about ‘conditions’ not ‘diseases.’[113]

Language is not something that should be subject to any formal policy. To be clear, this author is not advocating for the introduction of any negative repercussions for people who use unpreferable language. Rather, positive initiatives such as the Canadian Down Syndrome Society's "Anything But Sorry" campaign[114] and the "Congratulations Initiative" in Australia can spread awareness and encourage people to shift the language they use.

Upon receiving a diagnosis of Down syndrome, prospective parents should be advised of both the governmental and private supports available to them while still considering their options, not only after a decision is made to keep the baby.

Beyond the medical community, everyone can be encouraged to make small language changes in solidarity with people with Down syndrome and to affirm the value of all lives. For an example of common but likely discriminatory language that should be challenged, one mother expressed to this author how she was perplexed by remarks from family members during her pregnancy that, "We do not care if the baby is a boy or girl, as long as it's healthy." While this mother felt that they did not intend any harm by the statement, she was left to wonder if they equated "healthy" with not having a congenital condition and what it would mean for them and their relationship if the baby had Down syndrome.[115] It may be better to say, "I hope there are no health complications and everything goes smoothly."

Advocates have also stated it is not accurate to say that someone is "suffering from" Down syndrome, as people with Down syndrome often lead fulfilling lives. The Canadian Down Syndrome Society further states that "a person should not be defined by their disability," and that the person should be emphasized first. For example, it should be "the child has Down syndrome" or "my friend has Down syndrome" instead of "the Down syndrome child."[116]

3) Require genetic counsellors to meet people with disabilities

MyHealth.Alberta.ca explains genetic counsellors as follows:

> Working as part of a medical team, genetic counsellors provide education and support to families at risk for or diagnosed with inherited conditions. The counsellor can help people understand the pros and cons of genetic testing. They can also help explain which tests may or may not be right for each person. Genetic counsellors can explain test results and how inherited diseases might affect someone or their family.
>
> Genetic counsellors have graduate degrees and experience in the areas of medical genetics and counselling. Many genetic counsellors have worked in other areas, such as nursing, psychology, public health, or social work.
>
> Licensing, certification, and registration requirements for genetic counsellors vary from province to province.[117]

This description does not list the requirements to practice within Alberta, instead only indicating that requirements vary from province to province. The Government of Alberta or AHS should inform Albertans what they can expect from genetic counsellors operating within the healthcare system.

The government should ensure that genetic counsellors operating within the province's healthcare system have met people with Down syndrome and other genetic conditions. Based on publicly available materials, this does not appear to currently be a requirement.

Medical Genetics programs are offered at the University of Calgary and the University of Alberta,[118] the latter of which offers the course MDGEN 407/507 – Independent Studies in Genetic Counselling. While the course might include exposure to people living with disabilities, the description provides no indication that it does.[iii]

The Canadian Board of Genetic Counselling (CBGC) offers certification for genetic counsellors, but it is voluntary to obtain. The genetic counselling profession is currently unregulated.[119] The CBGC uses a Core Competency framework which includes both "Knowledge Based Competencies" and "Practice Based Competencies."[120] None of the 61 knowledge-based or 76 practice-based competencies explicitly mention meeting people with disabilities. If certified genetic counsellors in Canada do not actually need to know people with disabilities, this is an area for improvement.

Steps should be taken to ensure Alberta's genetic counsellors have spent time outside of a medical setting with families and individuals who have disabilities or genetic conditions, as do the graduates of the Master's in Genetic Counseling program at Brandeis University in Massachusetts.

4) Affirm doctors in complying with their conscience

As noted earlier in this paper, clinical practice guidelines in Canada recommend that all pregnant women be offered prenatal screening. A Canadian physician informed this author that doctors might be frowned upon if their patients do not opt for testing, and that doctors must carefully document why a patient has declined.[121] This may be due in part to the potential of wrongful birth litigation if prenatal screening or diagnostic testing is not offered. However, in the process of a physician meticulously documenting why a patient does not want prenatal testing, the patient may feel the questioning to be a form of pressure. Arguably, in the interest of informed consent, the onus should be reversed, with doctors asking patients to consider why they want to undergo prenatal testing and what they would then do with the information. Physicians may be required to inform all patients that they have the option to undergo prenatal testing, but they should take care that women are not pressured into it.

[iii] The description is as follows: "An interactive course designed to provide graduate students insight into the role of a genetic counsellor through exploration of key topics. The class meets once a week for a 2-to-3-hour discussion. Each week students will be presented a typical genetic counselling case, which they will then write up and present to the entire class the following week. All students will then participate in the discussion of the case. Midterm and/or finals consist of a 60 min presentation on a choice of various ethical issues currently impacting the field. The course is graded based on presentations, written assignments and participation. Open to up to 4 students with permission of the course instructor." University of Alberta, "MDGEN 507-Independent Studies in Genetic Counselling," accessed February 7, 2025, at https://calendar.ualberta.ca/preview_course_nopop.php?catoid=44&coid=508229.

While some medical professionals may be uneasy about supporting prenatal testing due to their views on abortion, it is important to recognize that some parents opt for testing without any intention of terminating a pregnancy even if the results return positive. Some parents would appreciate time to research and prepare to care for their child with a disability. This intention has been communicated by parents to this author as well as confirmed in studies. In a survey conducted of 882 pregnant women in Alberta and three other provinces in 2015-2016, 27% of participants responded that they were interested in knowing in advance if their baby had Down syndrome so that they could prepare themselves better to raise the child.[iv][122]

Moreover, one 2004 study states:

> Mothers [who knew ahead of time] were generally happier over the birth of their infant with Down syndrome than their counterparts who had received the diagnosis postnatally. This difference might stem from the fact that mothers who received a prenatal diagnosis tended to resolve any grief before their child was born.[123]

However, in accordance with the Canadian Medical Association Code of Ethics, physicians have a right and duty to practice in compliance with their conscience, as long as they provide sufficient notice to the patient to see another physician.[124] Physicians in Alberta already have this right, and this right must be upheld.

5) Continue data collection and monitor the ongoing development of NIPT

Governments and advocacy groups should continue to collect and publish data and statistics to inform future policymaking. The Public Health Agency of Canada published the "Down Syndrome Surveillance in Canada" report covering the years 2005-2013.[125] Since NIPT was introduced in Canada in 2013, it will be valuable to note if the number of births of children with Down syndrome remains steady or not.

If the Government of Alberta considers funding NIPT for more pregnant women as part of standard prenatal screening, it must carefully consider the underlying message it sends by doing so.[126] According to Dr. Saxton, NIPT "exploits the culture's fear of disability and makes huge profits for the biotech industry."[127] NIPT had a global market value of $3.9 billion in 2019 and continues to grow.[128] Is financially supporting this industry the best use of tax dollars?

However, NIPT represents a safer option than CVS or amniocentesis if parents are willing to forego invasive diagnostic testing in favour of NIPT. NIPT is more accurate than traditional screening methods but less accurate than diagnostic testing. But if parents plan to terminate a pregnancy due to NIPT predicting a congenital condition, they should first undergo diagnostic testing to confirm, because at that stage the risk of miscarriage is irrelevant if the plan is termination anyway.

[iv] Fifty-three percent of respondents said they would consider termination if the baby was diagnosed with Down syndrome.

6) Affirm the value of all lives and support inclusivity

Professors in the field of disability studies write: "Disability advocates are challenging … unquestioned assumptions at the very heart of so many debates over disability and social policy. They are asking why it is that disability—rather than bad social policy —is always identified as the problem to be solved."[129]

The Government of Alberta has a significant role to play in supporting Albertans with Down syndrome to live healthy and fulfilling lives. Some measures are symbolic while others are practical.

In December 2011, the United Nations General Assembly declared March 21 as World Down Syndrome Day.[130] By happenstance, this is also the date that Alberta's sterilization law received royal assent back in 1928. On that day in 2020, 2021, and 2022, official statements of support were released by Premier Jason Kenney, Health Minister Tyler Shandro, and Premier Jason Kenney, respectively.[131] Canadian Down Syndrome Week was also acknowledged by Premier Jason Kenney in November 2020. The Government of Alberta should continue to recognize days dedicated to supporting Albertans with Down syndrome and other genetic conditions.

In a 2020 study, Canadian researchers expressed the concerns of pregnant women, their partners and families about a possible future reduction in resources available for people with Down syndrome in the event the public healthcare system further routinizes prenatal screening and pressures parents to terminate pregnancies.[132] Economic circumstances can make raising a child seem overwhelming at the best of times, and no doubt even more overwhelming if the child has a disability. In light of these concerns, the government should offer reassurances to parents that despite providing prenatal testing and the option to terminate pregnancies, supports will not disappear for families who welcome children with disabilities into the world.

The Government of Alberta can also continue to support people with disabilities by creating additional post-secondary opportunities and supporting organizations and companies that assist with job placements. Alberta introduced micro-credentials in 2021.[133] The government could explore introducing micro-credentials for people with Down syndrome, like what has been introduced in Ireland.

Conclusion

Women and their families may be without children today that they would have wanted had they received different information or supports during pregnancy. They may have been misinformed about the realities of living with their child's specific condition and made the choice to terminate based on that misinformation. Parents of living children with Down syndrome have attested to the fearmongering they were subjected to before their children were born and noted that their actual parenting experience has been positive and much different than they were told to expect.[134]

Pregnant women may have also chosen to undergo invasive diagnostic testing that led to miscarriage because they did not fully comprehend the risks associated with the procedure.

This paper does not include a recommendation to remove access to abortion. It is recommending that the Government of Alberta take steps supporting neutrality within the healthcare system that currently sees women pressured by medical practitioners to not keep their babies. Dr. Saxton writes, “The reproductive rights movement emphasizes the right to have an abortion; the disability rights movement, the right *not to have to have* an abortion.”[135]

Professors Ferguson, Gartner, and Lipsky lament:

> From selective abortion to selective suicide, the disability community sees a mounting social threat to their existence just at the time when they are beginning to benefit from a generation of legislation and advocacy. Of course, none of this is meant to minimize the hard choices that specific couples must make in specific situations, with whatever resources and prospects they happen to have available. It is not so much the parental choices that we challenge, as it is the assumptions and contexts within which health professionals inevitably frame those choices.[136]

This paper has provided an overview of our province’s history of ableism, as well as discussed research and various ethical deliberations related to prenatal testing. Albertans must consider whether our province’s dark history with eugenics is still influencing our society’s motivations behind prenatal screening today. Alberta has an opportunity to now show national and international leadership in affirming the value of people with disabilities.

The recommendations above are key areas the author has identified for further investigation and action within an Alberta-specific context. The Government of Alberta is positioned to implement policies at the provincial level that discourage discrimination and enhance women’s pregnancy journeys without removing reproductive choice from the individual. In conclusion, women and their families need to accurately understand the purpose behind prenatal testing and not be pressured by Alberta’s medical community to terminate a pregnancy if their baby has Down syndrome.

Charlotte Helene Fien, a woman with Down syndrome, may have said it best in a speech at the United Nations, “You can try to kill off everyone with Down syndrome by using abortion, but you won’t be any closer to a perfect society. You will just be closer to a cruel, heartless one.”[137]

Author and Disclaimer

Brianna Morris lives in the Edmonton region with her husband and young children. She has a Master's degree in Political Science from the University of Calgary.

Any error remains the sole fault of the author. The author made every effort to accurately represent all sources of information used. The author would have liked to speak with more medical practitioners operating within Alberta about the issues discussed in this paper and trusts this engagement could occur as the government explores implementing the recommendations.

The author carried out this research as a mom and an independent consultant. This paper does not necessarily reflect the positions of her employers or associates - past, present, or future. However, she hopes that all her associates support these sensible recommendations.

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