Jérôme Lejeune Foundation

Situation of persons with Down syndrome in Canada

Written Contribution: CRPD Examination of Canada prior to the Session March 2025

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Introduction

The Jérôme Lejeune Foundation is an international foundation with headquarters in Paris, France Created in 1995, after the death of Professor Jérôme Lejeune, the doctor who co-discovered the chromosomal origin of Down syndrome, it has been recognised as an organisation of public benefit since 1996. The Lejeune Foundation has delegations Spain, Argentina, and in the United States of America. Being at the service of the right to health of persons with intellectual disabilities of genetic origin: Fragile X, Rett and Angelman syndromes, etc. The most common and best known is Down syndrome (also called trisomy 21). The Jérôme Lejeune Foundation has three missions:

- medical research aimed at facilitating daily life and autonomy of persons with disabilities.
- make the right to health a reality by offering medical consultations with qualified doctors.
- protect the dignity of persons with disabilities.

The Jerome Lejeune Foundation is a global expert and leader advocate for the rights of persons with genetic intellectual disabilities.

This written contribution aims to provide an analysis of Canada’s compliance with the CRPD, particularly under Articles 5, 6, 8 and 25, with a focus on the rights and well-being of persons with intellectual disabilities, including those with Down syndrome. While acknowledging existing measures, this contribution highlights systemic shortcomings and provides recommendations for improvement.

Article 5: Equality and non-discrimination

Positive measures

The main federal laws which protect people with disabilities from discrimination include the Canadian Charter of Rights and Freedoms and the Canadian Human Rights Act.

Areas of improvement

Discrimination remains a significant barrier for individuals with intellectual disabilities in Canada, particularly when it comes to social inclusion and participation in community life. The stigma associated with intellectual disabilities often leads to exclusion, particularly in public spaces, recreational activities, and cultural events. According to the Canadian Human Rights Commission (2020), people with intellectual disabilities are more likely to experience exclusion and discrimination in education, employment, and healthcare. Despite legal protections, individuals with intellectual disabilities are frequently denied equal access to these spaces, either due to physical inaccessibility or societal prejudice. This exclusion perpetuates the marginalization of individuals with intellectual disabilities, reinforcing stereotypes and preventing them from enjoying the same quality of life as their non-disabled peers.

The Canadian government has demonstrated discriminatory attitudes toward individuals with Down syndrome, as highlighted by the case of Felipe Montoya, an environmental studies professor. Montoya secured a position at York University in Toronto and applied for permanent residency to relocate his family from Costa Rica to Canada. However, Canadian immigration officials rejected his application, citing his 13-year-old son Nico's Down syndrome as a potential "burden" on taxpayers. This decision sparked a lengthy legal battle as Montoya contested the ruling, arguing that his son was being unfairly discriminated against based on his genetic identity. The case underscores broader societal biases against individuals with Down syndrome, perpetuating harmful stigmas that portray them as chronically ill or in need of constant intensive care—misconceptions far removed from the reality of their lives.

According to the 2017 Canadian Disability Participation Project, the lack of awareness and education around disability issues perpetuates exclusion, which negatively impacts the opportunities for individuals with intellectual disabilities. The Convention on the Rights of Persons with Disabilities requires that all individuals with disabilities be included in society on an equal basis, and Canada must make concerted efforts to address these inequities.

Recommendations

Implement Public Awareness Campaigns: Canada should launch public awareness campaigns aimed at combating ableism and changing negative perceptions of individuals with intellectual disabilities. These campaigns should highlight the contributions and value of people with disabilities, promoting inclusivity and challenging societal stereotypes. By fostering a more inclusive attitude, these campaigns can reduce stigma and encourage greater acceptance of individuals with intellectual disabilities in all areas of society.

Enhance Accessibility in Public Spaces: The government should prioritize making public spaces, including cultural, recreational, and community spaces, accessible to all individuals, regardless of their abilities. This includes ensuring that buildings, transportation, and public events are designed with universal accessibility in mind. By improving physical and social accessibility, Canada can promote the full inclusion of individuals with intellectual disabilities, allowing them to participate fully in public and social life.

Article 6: Women with Disabilities

Positive Measures

Canada has implemented several initiatives to support women with disabilities, including intellectual disabilities. Laws such as the Canadian Human Rights Act and the Accessible Canada Act emphasize the importance of equal treatment and protection from discrimination.

Areas for Improvement

Despite these measures, women with intellectual disabilities, including those with Down syndrome, remain highly vulnerable to violence, abuse, and forced sterilization. Studies have shown that women with disabilities are up to three times more likely to experience gender-based violence than non-disabled women. Reports indicate ongoing cases of forced sterilization, often justified under the guise of "medical necessity" or "incapacity" to parent.

The Canadian Senate published in 2021 a report on Forced and coerced sterilization of persons in Canada. It was confirmed that "this horrific practice is not confined to the past but clearly is continuing today. Its prevalence is underreported and underestimated. The committee is deeply concerned that along with Indigenous women, other vulnerable and marginalized groups in Canada are affected, including women with disabilities, racialized women and institutionalized persons".

Bonnie Brayton, National Executive Director, DisAbled Women's Network of Canada, stated that "women with disabilities in Canada have been targeted for coercion and/or forced sterilization historically and remain vulnerable to these practices today." (…) "Canadian study found that young women with intellectual disabilities were commonly prescribed Depo-Provera in response to family and caregiver concerns around unwanted pregnancy and menstrual hygiene.”

The report also highlighted that amongst the factors which contribute to the vulnerability of forced and coerced sterilization of women with disabilities include lack of knowledge and stigma about disability from medical professionals.

Women with disabilities in Canada face disproportionately high rates of violence. Despite representing only 14.9% of the female population, they account for 45% of all reported incidents of violent crime against women. The risks are even greater for those who have experienced homelessness; women with disabilities in this group are three times more likely than their peers to self-report violent victimization.

Recommendations

Establish stronger monitoring mechanisms to prevent forced sterilization, ensuring compliance with Article 23 of the CRPD.

Provide specialized training for law enforcement and healthcare professionals on recognizing and preventing violence against women with intellectual disabilities.

Increase funding for accessible shelters and support services specifically tailored to women with intellectual disabilities.

Develop educational campaigns to empower women with intellectual disabilities about their rights and protections under Canadian law.

Article 8: Awareness-Raising

Positive Measures

Canada has made efforts to raise awareness about disabilities through initiatives like National Accessibility Week and public campaigns promoting inclusion and diversity.

Areas for Improvement

Awareness campaigns are not sufficiently targeting the issue of discrimination as systemic issues persist in the way Down syndrome is presented to the public, especially to expectant parents. Prenatal screening programs, including Non-Invasive Prenatal Testing (NIPT), are promoted without balanced information. Parents often receive disproportionately negative portrayals of Down syndrome, leading to high rates of pregnancy termination. A 2020 study found that over 90% of pregnancies with a Down syndrome diagnosis in Canada end in abortion. This reflects a form of prenatal discrimination and diminishes the dignity and value of persons with Down syndrome.

Parents receiving such diagnoses report overwhelming pressure to abort. Medical professionals often fail to provide balanced, neutral information, focusing instead on the challenges of raising a child with Down syndrome. Negative framing of the condition, combined with a lack of supportive resources, leaves parents feeling abandoned and coerced into termination. One mother described the absence of even a single pamphlet offering a positive perspective, highlighting a systemic failure to offer comprehensive and unbiased guidance.

Renate Lindeman, a mother of two children with Down syndrome said If we don't start giving pregnant women real information about Down syndrome before they are screened, I fear what will happen when a new generation of early, accurate and safe prenatal tests is commercially launched next year. In the near future, we can expect prenatal tests for many other conditions and diseases, such as a predisposition to autism or cancers. Who decides which conditions women should be screened for? Will people with identifiable conditions experience intolerance, financial hardship?

This situation perpetuates harmful stereotypes, portraying Down syndrome as a condition to be eradicated. Rather than supporting families or celebrating diversity, the healthcare system reinforces the idea that lives with Down syndrome are less valuable. This bias reflects a broader societal trend that prioritizes “normalcy” over inclusivity, marginalizing people with disabilities and perpetuating discrimination under the guise of choice.

In a Consultation on the Ethical Issues of Prenatal Screening for Trisomy 21, or Down Syndrome, in Quebec, made by the Commissioner for Health, it was revealed that prenatal screening increases discrimination. The report states: "It was brought to our attention that people with Down syndrome and their relatives suffer from discrimination and that their social integration is difficult. A fear was expressed that this situation could worsen with the implementation of a prenatal screening program."

The report also “emphasized that the content of the information provided during the offer of tests and the way in which it is delivered may, in some cases, not allow parents to make a free and informed choice about whether or not the woman undergoes the test, as well as whether or not to continue the pregnancy following the announcement of a positive diagnosis.”

Then the same report recommended: "To limit discrimination against people with intellectual disabilities and their families and to reduce the risks of transmitting discriminatory messages towards them, it is important to aim for a standardization of the information conveyed as part of pregnancy follow-up. Furthermore, more generally, awareness programs could help make known the reality experienced by people with Down syndrome and their families."

Canada’s approach not only neglects to challenge these prejudices but actively funds and promotes practices that support mass termination. The lack of balanced counselling and the overwhelming focus on termination signal systemic complicity in creating a culture where certain lives are deemed unworthy, undermining values of equity and inclusion.

Recommendations

Mandate balanced counselling and resources for expectant parents following a prenatal diagnosis of Down syndrome, ensuring they receive accurate, non-biased information.

Develop nationwide campaigns showcasing the abilities and achievements of individuals with Down syndrome to counteract stigma.

Train healthcare professionals to present Down syndrome as a liveable and enriching condition rather than as a “tragedy” or “burden”.

Review and regulate the promotion of NIPT and other prenatal screening technologies to ensure they are not implicitly advocating for the elimination of individuals based on their genetic pathologies.

Article 25: Health

Positive Measures

Canada provides universal healthcare access, which includes services for persons with disabilities.

Areas for Improvement

Lack of access to basic healthcare: a recent news report from January 2025 highlighted criticisms regarding the lack of support for families needing Down syndrome care in British Columbia where in 2018, Florence Girard, a woman with Down syndrome died of starvation and lack of care. Tamara Taggart, president of a Down syndrome advocacy group, highlighted the dire need for funding support for families and caretakers of individuals with developmental disabilities. She further explained how families face immense financial burdens for essential therapies (for example, $12 000 for a therapy to learn how to eat solid food) and the lack of help from the authorities.

An article titled “Turned down by child-care providers, Ontario mom says 'huge stigma' persists for babies with Down syndrome” published in 2023, tells the story of Trish Jarvis. This Ontario mother has been unable to find child care for her daughter Farley, who has Down syndrome, after contacting over 30 providers in nine months. Ms Jarvis stated that "Even hearing there's a syndrome or disability involved, they -health care providers- think it's the big bad wolf of a baby". She added: "There's this huge stigma like it's one of the worst things in the world."

Heather Gain of the Down Syndrome Association of Hamilton and professor Kathryn Underwood emphasize that discrimination and a lack of resources in child care are significant barriers, worsened by the pandemic. Andrea Brown, another parent, eventually found care for her son with Down syndrome after two years, but it is far from ideal, adding significant strain to her daily life. professor Kathryn Underwood calls for better oversight and policies to combat discrimination and ensure inclusivity for children with disabilities.

“Farley has a syndrome, but that doesn't define her. She will thrive in her own unique way", the mother concluded. It is deeply concerning that Canadian federal and local authorities fail to provide standard healthcare for individuals simply because of their disabilities. The Canadian government must do better in upholding the right to health, which serves as the foundation for all other rights.

Research Funding Bias: Despite these efforts, there is a significant lack of government funding for research aimed at improving the quality of life for individuals with Down syndrome. Instead, resources are disproportionately allocated toward prenatal screening programs, prioritizing the prevention of Down syndrome births rather than supporting those already living with the condition.

A 2018 presentation examined funding patterns for Down syndrome research at the Canadian Institutes of Health Research (CIHR) from 2000 to 2016. The study highlighted potential biases, noting that a significant portion of funding was directed towards prenatal testing and screening programs, potentially at the expense of research directly benefiting individuals living with Down syndrome. The report highlighted that commercial incentives might be influencing funding decisions, disadvantaging clinical and social science research that could improve the quality of life for those with Down syndrome.

Euthanasia Concerns: Canada's euthanasia law, known as Medical Assistance in Dying (MAiD), has been expanded to include individuals with serious illnesses, diseases, or disabilities, even if their deaths are not imminent. This broadening has raised significant concerns among disability rights advocates and international bodies regarding its potential discriminatory impact on vulnerable populations, including those with Down syndrome. Instead of protecting them from such practices due to their vulnerability, Canada is further pushing persons with Down syndrome towards the edge of society.

In 2021, the United Nations Human Rights Council's special rapporteur on the rights of persons with disabilities criticized Canada's euthanasia law for undermining disabled individuals' equal right to life and their ability to access support to continue living. The rapporteur highlighted that the law appeared to violate international human rights standards by having a discriminatory impact on disabled people.

Furthermore, disability rights groups have legally challenged Canada's assisted death framework, arguing that offering euthanasia to individuals whose deaths are not imminent infringes on their rights to equality, life, liberty, and security. They contend that the availability of assisted death for non-imminent conditions can pressure disabled individuals into ending their lives due to inadequate support systems.

Individuals with intellectual disabilities, such as Down syndrome, may lack the capacity to make fully informed decisions regarding euthanasia due to their intellectual disabilities. This raises ethical concerns about their ability to consent and the potential for undue influence or societal pressures to opt for assisted death. The expansion of MAiD to include non-terminal conditions has led to doubts and concerns even among medical professionals about the adequacy of safeguards to protect vulnerable populations. “On private forums, doctors and nurses have expressed deep discomfort with ending the lives of vulnerable people whose deaths were avoidable, according to messages provided to AP by a participant on condition of anonymity due to their confidentiality.”

Recommendations

Reallocate funding to prioritize research on Down syndrome and other intellectual disabilities, focusing on medical advancements and daily living supports.

Amend MAiD legislation to exclude individuals with intellectual disabilities.

Develop health programs tailored to the unique medical needs of individuals with Down syndrome, including regular access to specialists.

Conclusions

Canada's commitment to the rights of individuals with intellectual disabilities, particularly those with Down syndrome, has made significant strides through legal frameworks and public initiatives. However, challenges remain in achieving full inclusion and respect for their dignity. Discrimination, whether in the form of exclusion from healthcare, or societal participation, continues to impede the integration of individuals with intellectual disabilities into everyday life.

The existing laws and policies often fail to address the deeper, systemic issues that contribute to exclusion and marginalization. This is especially evident in areas such as prenatal screening and healthcare access, where biases and a lack of comprehensive support continue to perpetuate harmful stereotypes and inequality. The need for balanced and non-biased information, especially regarding Down syndrome, is critical for empowering families to make informed decisions free from coercion.

Additionally, the vulnerability of women with intellectual disabilities to violence, abuse, and forced sterilization underscores the urgent need for more robust protection mechanisms and education on their rights. The current gaps in services, particularly in healthcare and childcare, further highlight the necessity for a more inclusive approach to caregiving and support for individuals with disabilities.

To foster a truly inclusive society, Canada must strengthen its efforts in public awareness, accessibility, and support services. A comprehensive and holistic approach, focusing on eliminating discrimination, promoting equality, and ensuring access to essential services, is needed to fully uphold the rights of individuals with intellectual disabilities. By making these improvements, Canada can work toward ensuring that all individuals, regardless of their abilities, are able to live with dignity, autonomy, and respect in a society that embraces their contributions.