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Children with disabilities in Canada:

Alternative Report for the 5th/6th Review of Canada

Under the Convention on the Rights of the Child

Submitted by the Participation and Knowledge Translation in Childhood Disability lab

to the United Nations Committee on the Rights of the Child

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I. INTRODUCTION

“States Parties recognize that a mentally or physically disabled child should enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance, and facilitate the child’s active participation in the community.”

Article 23 of the United Nations Convention on the Rights of the Child (UN CRC)

Canada has a commitment to children with disabilities through its ratification of two United Nations human rights treaties: The Convention on the Rights of the Child (CRC) and the Convention on the Rights of Persons with Disabilities (CRPD). Important advances have been made since the last report on the CRC, and significant points pertaining to children with disabilities have been raised in the first report to the CRPD in 2016.

Nevertheless, Canadian children with disabilities and their families continue to face challenges in realizing their basic rights. The last national dataset about children with disabilities in Canada dates of 2006. According to this survey, 298,410 young Canadians under 15 years old (a rate of 10.9%) have an identified disability (HRSDC, 2011). These numbers do not account for children and youth 15 and older, who are also protected by the CRC, but are grouped in Canadian datasets within adults and specific data has not been estimated for this age group. The total number is an underestimation of the current number of those affected given the discontinuation of child disability data collection in over a decade. Notably, the impact of disabilities goes beyond the child and relates directly to the families and communities surrounding them.

Children with disabilities are members of multiple groups of children who face discrimination and marginalization in Canadian society. Living with a disability can result in significant inequities in different areas of a child’s life. Challenges faced by Canadian children with disabilities include unequal access to healthcare, social services, and education (Green et al., 2005; WHO, 2011). Children with disabilities also participate less in civil life (community life, social leisure activities) when compared to children without disabilities (Engel-Yeger et al., 2009). Barriers at the community, organizational, and public policy levels limit their participation in society and are first encountered in the early years and persist into adulthood (Emerson & Baines, 2011; Green et al., 2005; Woodgate et al., 2019; UNICEF, 2007; WHO, 2011). These barriers put children with disabilities at risk of poor health, low educational attainment, unemployment, poverty, exclusion, and discrimination (Emerson & Baines, 2011; WHO, 2011) and hinder their enjoyment of full citizenship (Acharya et al., 2017). These disparities can be more pronounced for those who have a disability and are also undergoing other layers of systemic marginalization such as children who live in a low-income setting, indigenous, ethnic minority, refugees, immigrants or those who identify themselves or whose parents identify as LGBTQI2S. Data on the situation of these children in Canada is lacking and therefore there are important challenges in identifying the real needs of this group.

In this report, we briefly outline issues faced by children with disabilities in Canada based on research evidence and the lived experiences of parents and youth, areas of opportunity in relation to these issues, and recommendations that can begin to address these problems. We also present testimonials provided by parents of children with disabilities that highlight positive developments as well as areas of opportunity. This report does not purport to be comprehensive but presents information provided by the authors based on their work/expertise and/or lived experience as it relates to each topic, with emphasis on aspects related to health services, the right to play, and health and social policy.

Key recommendations made in the Concluding Observations to Canada in relation to Children with Disabilities included:

- (a) Establish as soon as possible a system of global and disaggregated data collection on children with disabilities, which will enable the State party and all its provinces and territories to establish inclusive policies and equal opportunities for all children with disabilities;
- (b) Ensure that all children with disabilities have access, in all provinces and territories, to inclusive education and are not forced to attend segregated schools only designed for children with disabilities;
- (c) Ensure that children with disabilities, and their families, are provided with all necessary support and services in order to ensure that financial constraints are not an obstacle in accessing services and that household incomes and parental employment are not negatively affected; and
- (d) Take all the necessary measures to protect children with disabilities from all forms of violence.

II. SITUATION OF CHILDREN WITH DISABILITIES IN CANADA

Cluster 1: General Measures of Implementation

Statistics and Data Collection

Issue and Evidence: The situation highlighted in the report to the 5th/6th report to the CRC and on the 1st report to the CRPD is still true: data on children with disabilities is lacking, with last census data on children with disabilities dating from 2006 (Dunn & Zwicker, 2017). Further, most available data on disability is cross-sectional with a paucity of longitudinal data on the experiences and outcomes for these children and their families. These limitations hinder the development of adequate programs, policies, and regulations to address critical needs. To address this lack of data, disability-related questions (based on questions proposed by the Washington group) were added to the 2019 Canadian Health Survey on Children and Youth (CHSCY). Data from that cycle of the survey will be available in March 2020 and will provide information regarding child functioning, long-term health conditions, accessing healthcare for various conditions, difficulties experienced when accessing services, and services received/required from various healthcare professionals.

Area of Opportunity: Although data from the 2019 CHSCY will provide useful information on health-related aspects of children with disabilities, many areas of their lives will remain undocumented.

Recommendations

Strengthen and update the evidence-base to inform policy, planning, and decision making by improving disability data collection:

Ensure data is collected on various aspects of children's lives such as: enrolment of children with disabilities in schools, proportion of staff trained and involved in disability and child-related programs, poverty indicators, living and housing conditions for children of all disability levels, number of children undergoing painful and invasive medical procedures, and healthcare expenditures.

Collect longitudinal data on experiences, outcomes, & impact of disability on both children and their families (WHO & the World Bank, 2011)

Collect data on young children with disabilities to guide service provision and social and policy systems (WHO & the World Bank, 2011)

Enhance psychometrics of data collection instruments (WHO & the World Bank, 2011)

Collect disaggregate data on disabilities (by type of disability) to contribute to the assessment of the current situation of children with disabilities and their families and to develop goals and programs based on real needs.

National Implementation and Monitoring

Issue and Evidence: Currently in Canada there is no systematic monitoring of the CRC or CRPD implementation. The Canadian Human Rights Commission has received a designated role to develop a monitoring mechanisms for the CRPD, however the monitoring of the CRC still relies on Civil Society Organizations and independent advocacy organizations. This non-coordinated action creates space for duplication and misses opportunities for collaboration.

The federalist system in Canada is also a barrier for implementation given that federal government often attributes the responsibility for essential services and provisions on the provinces. A coordinated action to respond to previous reports and ascertain compliance by the provincially-based services and policies is necessary and urgent.

Area of Opportunity: CRPD monitoring mechanisms are being put in place in the context of the Accessible Canada Act implementation. Indicators for the CRPD have been thoroughly developed by the UN Office for the High Commissioner in Human Rights (<https://bridgingthegap-project.eu/crpd-indicators/>) and are being developed to the CRC (<https://crcindicators.uvic.ca/index.php/content/overview>)

Canada has a unique opportunity to develop a twin track approach to the monitoring and implementation of both conventions through these indicators applied to the Canadian context.

Recommendations

To establish a twin-track for monitoring and implementation of the CRPD and the CRC considering the specific needs of children with disabilities and their families

The Canadian Human Rights Commission, key partners in the civil society, representatives of different disability groups and children's rights groups (including groups in the disability and child rights that represent minorities within these groups such as indigenous, immigrants, refugees, LGTBQ2S) and academic researchers should convene a strategic planning. The goal should be to develop a twin-track approach that includes: CRC and CRPD indicators, common elements identified in previous reports for the CRC and CRPD, and concrete data being collected at the current Child Health Longitudinal Survey, research datasets, and administrative datasets related to education and social and community services to identify gaps in the realization of basic rights for children with disabilities, and propose solutions to be monitored in the next reporting cycle for both the CRC and the CRPD.

Cluster 5: Disability, Basic Health and Welfare

Health and Health Services

Issue and Evidence: In Canada, programs for children with disabilities are provided at both the federal and the provincial/territorial government level. These programs are an essential component to fulfilling UN CRC Article 23, outlining the need for children with disabilities to “enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active participation in the community.” Supports provided by the Federal government are primarily delivered through the tax system, in the form of tax credits, tax deductions, and tax-free benefits. The primary purpose of these programs is to promote horizontal equity, or to recognize and aim to offset the additional costs associated with raising a child with a disability. The notable exception to this is the Registered Disability Savings Plan (RDSP), which is designed to incent savings by parents/caregivers for financial support in the long term. Programs provided by provincial/territorial governments in Canada provide the majority of support for children with disabilities and their families. These programs include tax measures, financial assistance programs, social support programs, home care programs, assistive devices programs, accessibility modification programs, early intervention programs, and prescription drug coverage programs.

Area of Opportunity: Despite the potential access (available services) provided through the existence of government-funded disability programs, there are low rates of realized access or actual use of these services (Aday & Andersen, 1974). This suggests that there is a need for better access to disability programs to improve

health capacity for children and youth with disabilities. Ninety per cent of youth with developmental disability in Canada need access to services and professional supports spanning health, education and social services, and access to these services was identified as a critical gap across all Canadian provinces (Clark, Clark, & Seel, 2009). Challenges to realized access result from different priorities, mandates and approaches to service delivery across ministries (environmental factors), inconsistent policies, distinct eligibility criteria (individual factors), and a lack of data on service use provided across the continuum of care (Clark et al., 2009; Kuo et al., 2011; Quigley et al., 2014; Wiart et al., 2010).

In an effort to evaluate the realized access to programs for children with disabilities in Canada, the Health Policy team at the University of Calgary's School of Public Policy has compiled a database detailing what provincial governments are spending on disability programs, and how many people are accessing these programs, over the past two decades, where available. To make this information more accessible, we have also visualized this database online (Disability Data Project). In creating this database, we found that standardized and comprehensive data on government disability programs are not available in every province/territory and for every program, suggesting a need for improved program-level data in Canada.

Recommendations

Governments across Canada should regulate and standardize the collection of data with respect to children with disabilities and the programs that support them, to ensure that data are consistent across jurisdictions and over time, and are comprehensive.

This will ensure that Canada can adequately evaluate realized access to disability programs for children with disabilities. This will allow Canada to determine whether government programs are adequately meeting the needs of children with disabilities and their families, and, by extension, meeting the requirements under Article 23 of the UN CRC.

Measures to ensure dignity, self-reliance and active participation in the community

Issues and Evidence: Several services and supports are required to ascertain active participation in the community for children with disabilities. This includes, but is not limited to respite care for families, tax supports, and equipment that facilitates community mobility and social interactions. In this report we highlight the provision of mobility and assistive communication devices as one example of measures that should be taken to support dignity, self-reliance and active participation. Various mobility aid programs are available across Canada to assist families with the cost of caring for a child with a disability. These programs provide financial assistance to families who wish to purchase equipment such as wheelchairs, scooters, ramps and other mobility devices. These programs include the Accessing Mobility Aids available provincially (i.e., in Saskatchewan, Quebec, Alberta, Ontario, and British-Columbia) (Childhood Disability Link, n.d.). Examples of these programs include "The Prince Edward Island AccessAbility Supports program", that extends to providing personal and community support as well. Other programs offer funding for making the home accessible for the child. For example, the Access-A-Home program in Nova Scotia provides support for making the home wheelchair accessible (Childhood Disability Link, n.d.). Therefore, although some programs may cover mobility aids, some may not necessarily cover home modifications. While coverage and eligibility requirements differ across programs, all these programs are designed to help children with disabilities live more autonomous lives. Despite the availability of these provincial mobility aid programs, many children do not receive the adequate support needed resulting in unequal access to personal mobility opportunities. Mobility across different environments and settings is also a challenge: sometimes children have access to certain equipment and adaptations in the school setting, but not in the home and community settings, limiting their participation in all the important contexts of life. The ability to maintain the equipment, update, and adapt equipment as children grow older is often neglected when children transition from pediatric to adult settings (depending on the legal age parameters that varies across provinces: from 18 years old to 24 years old). The ability to maintain equipment and services has an important impact on the continuing participation of children and youth as citizens. For instance, children may lose access to assistive communication devices that allow for them to express their voices through computerized programs for children

who are not verbal, as they reach the age limit to be in an school setting. Without these supports, youth may not be able to express their views. Similarly, powered wheelchairs may also not be available in the home and community setting, if they are provided through the educational setting, limiting child's ability to participate in the community. Families have also reported that within Canada, you may lose specific benefits, services, and provisions when transitioning across provinces.

Area of Opportunity: Services offered across provinces could be harmonized, funding policies with respect to the eligibility requirements, coverage limitations, and other criteria that vary across Canada should be revisited to make sure that children have access to the same participation opportunities regardless of provision being through education (e.g. equipment that is provided in the school setting only) or health (equipment and resources provided through health and rehabilitation services), can access services across their life span and according to their evolving abilities, and respecting the choices for where their families live (Smith et al., 2018).

Recommendations

Improve equal funding allocation for families of a child with a disability:

Establish clear definitions of the different types of mobility devices, communication devices and other equipment and supports that are covered by provincial governments across the country, and in the different age stages of the child, respecting the evolving capacities of children and supporting their citizenship and participation.

Establish consensus on what is considered basic or essential use for mobility devices (Smith et al., 2018)

Provide mobility funding to individuals with a disability regardless of age, residence, or health condition (Smith et al., 2018)

Determine coverage and help choose the funding program based on assessed need (Smith et al., 2018)

Cluster 6: Education, Leisure, and Cultural Activities

Participation in the community, Play, and Rest

Issue and Evidence: Despite the benefits and importance of participation and the right to play, participation of children with disabilities in leisure activities, including opportunities for free play, physical activities, play in public parks and playgrounds, outdoor play and structured play activities is restricted in comparison to that of other children (Bedell et al., 2013). Particularly for Canadian children, research indicates ongoing reduced opportunities to play and participate in various leisure activities, with even more reduced opportunities as children grow older (Law et al., 2006; Majnemer et al., 2008; Shikako-Thomas et al., 2012). Restrictions on the right to play are enacted in playgrounds, parks, community centers, museums, arts and sports venues – public spaces that should be owned, used, explored and enjoyed by all. The data from the 2006 PALS demonstrated that among Canadian children with disabilities aged 0-4 years, 69.7% reported mild or moderate disability while playing and 8.8% reported severe disability while at play. Among children 5-14 years old, 44.3% reported disadvantage in transportation or leisure, illustrating some of the many barriers that exist in the environment (PALS 2006). Research on accessibility of playgrounds for children with disabilities in Canada (Yantzi et al, 2010; Ripat et al, 2012; Dietze, 2013; Movahed et al, in preparation) shows existing barriers for children with disabilities to fully play in playgrounds include lack of universal accessibility standards that take into account the variability of disabilities, poor enforcement mechanisms, and the lack of overall monitoring to support the provision of inclusive public play spaces.

Supports and policies that exist across Canada are inconsistent, do not cover different areas of leisure and play such as social barriers and accessibility standards for children, and vary across provinces, creating inequities across the country, and not affording opportunities for monitoring. The WHO's International Classification of Functioning, Disability, and Health framework (ICF) recognizes the importance of identifying environmental barriers and facilitators for both participation and the capacity to participate. The Environmental Factors domain

of the ICF includes physical, social and attitudinal environment in which people live.

Within the new Accessible Canada Act, specific measures exist to promote the creation of Accessible Environments for Canadians with Disabilities. However, no specification exists to understand an apply these standards according to the needs of children. Considerations of barriers and facilitators that are most relevant for children with disabilities to have their right to play respected must be applied to areas such as cultural activities, leisure, and participation in the community at large.

Regarding the "Right to Rest" for children with disabilities and their families, research indicates that up to 85% of children with neurodevelopmental disorders have sleep problems, compared with 25% of typically developing children (Horwood et al., 2019). The lack of adequate sleep and rest can impact development, learning, and other basic opportunities for meaningful participation for children.

Areas of opportunity: The Accessible Canada Act has specific concerns with regards to several areas that can impact children's participation and living in the community. Standards for implementation are currently being developed and could benefit from a children's right impact analysis.

Multiple opportunities for collaborations with regards to accessible and inclusive play could occur within the context of national policies and strategic programs such as capitalizing on the Jooay App (www.jooay.com), the ParticipACTION campaigns, provincial inclusive initiatives (Carrefour Action Municipal), and the Better nights Better Days initiative to implement health promotion standards that include play and rest.

Recommendations

To develop a Children's Right Impact Assessment for the Accessible Canada Act and policies and standards developing from all the implementation process.

To use measures that are being developed in academic settings and community settings such as the Child Community Health and Inclusion Index (Eisenberg et al, 2015) to determine standards of accessibility for Canadian Children and consider children with disabilities unique needs in Canadian context to assess or benchmark actions and policies, including opportunities for consultation with children and youth with disabilities and their families.

To include child factors within accessibility monitoring and implementation planning.

To create mechanisms that coordinate programs nationally in aspects related to inclusion, accessibility, and health promotion opportunities including contextual factors and a variety of environments where children live such as educational settings, community settings, and health sector towards a common goal of promoting the right to play broadly.

Action should be done towards developing, implementing, and monitoring the effectiveness of policies and guidelines on inclusive play spaces to support participation of children with disabilities in play.

Cluster 7: Special Protection Measures (Inclusive policies and provisions)

National Autism Strategy

Issues and Evidence: In 2019, Canada has committed to developing a National Autism Strategy under the mandate of the Minister of Health, supported by the Minister of Minister of Employment, Workforce Development and Disability Inclusion.

Autism is a pervasive developmental condition affecting 1 in 66 children in Canada, whereas boys are four times more likely to be diagnosed than girls. This makes autism the most common neurological condition in Canada (Oftner et al., 2018). Since some of the challenges are not considered medical in nature, most families pay out of pocket for supports. The lifetime cost of autism for one person (including medical, community-based support, and

loss of employment income) is estimated to range between \$1.2 million and \$4.7 million depending on the level of functioning of that person (Amendah et al., 2009, Dudley & Emery, 2014). Further, Canadian families from low socioeconomic status wait longer before receiving services for their children because of fewer supports available in the public sector (McLaughlin & Schneider, 2019). Canadian caregivers spend approximately 14 hours per week facilitating service provision, and sacrifice jobs, saving, and their homes (McLaughlin & Schneider, 2019). Because Canada is a vast country geographically, caregivers may experience higher out-of-pocket costs because of travel to access autism services. This includes time taken away from work, which is especially true for families in rural and remote areas. These out-of-pocket costs can vary between \$51,251 to \$108,816 per year depending on remoteness (Tsiplova et al., 2019).

There is also a gender difference where girls who meet the criteria for autism are at a high risk of not receiving a clinical diagnosis (Loomes et al., 2017). This diagnostic gender bias means that the current literature on service needs and utilization may not reflect those of the population.

Area of Opportunity: Canada may be able to use the National Autism Strategy to employ monitoring of autism and align indicators in this with other disabilities, feeding into domestic and international reporting. Engagement of civil society organizations that speak as a collective will be important to ensure impact for families. Encouraging the use of rights-based language in the Strategy so that it can be a first step and one piece that will align with other disability plans.

Different research-based, stakeholder-driven initiatives have been funded in Canada to bring together the childhood disability community. Examples include the CHILD-BRIGHT network (www.child-bright.ca) and the Kids Brain Health network (www.kidsbrainhealth.ca). These networks exemplify a timely opportunity to strengthen the community of children and families towards common goals (health promotion), and to actively include children and youth voices through panels, advisory boards and active partnership, and to connect research data with policy and service provision.

Recommendations

Strengthen and update the evidence-base to inform policy, planning, and decision making by improving disability data collection across all childhood disability groups and not only autism:

Benchmark best practices and exchange information about outcomes of different provincial and territorial services

Facilitate consultations for high need areas (e.g. remote and Indigenous populations)

To develop a Pan-Canadian surveillance data for resource planning, capitalizing on and expanding from existing initiatives.

Accessible Canada Act

Issues and Evidence: In Canada, stakeholders and disabled persons organizations continue to lobby for the right of persons with disabilities to enjoy full equality in society. The Government of Canada has taken a step forward in this regard with the introduction of Bill C-81 or the Accessible Canada Act (ACA). Through the introduction of this Act, the Government of Canada seeks to protect the rights and dignity of persons with disabilities, contribute to their equality of rights, and ensure their inclusion in society and enjoyment of full citizenship. The ACA was proclaimed into force in July 2019. This Act has a solid human rights foundation and calls for a barrier-free Canada where all Canadians, especially persons with disabilities, enjoy full citizenship (Council of Canadians with Disabilities, 2013). The ACA Principles state that: (1) all persons must be treated with dignity and must have the same opportunity as everyone else to live the lives they wish to live, (2) all persons must have barrier-free access to full and equal participation in society regardless of ability or disability, (3) all persons must have meaningful options and be free to make their own choices regardless of ability or disability, and (4) persons with disabilities must be involved in the development of laws, policies, programs, services, and structures and these

must take into account the abilities and disabilities of all persons (Accessible Canada Act, 2019). Thus, the ACA empowers the government and other regulators to create new accessibility regulations that will set legal requirements for designated organizations to make their services, employment, built environment, and other areas more accessible.

Area of Opportunity: The ACA does not mention children and thus, it is unclear how the Act applies to children with disabilities. Also, most areas related to children with disabilities are not within the scope of federal legislation (they fall under provincial/territorial jurisdiction) and lack central regulation or monitoring. The lack of central monitoring creates inequities in distribution of services across provinces. Further, although the Accessibility legislation has included consultations with persons with disabilities, disabled persons organization, and youth, these consultations have not included younger children, children with multiple disabilities, from rural areas and Indigenous communities, or those who use non-verbal forms of communication.

Recommendations

Amendments to the Accessible Canada Act must be made to identify how the Act applies to children. That is, special provisions and considerations should be made for children and youth as the new legislation gets implemented at the federal and provincial levels. Considerations can include coherent, regulated, and monitored mechanisms of collaboration between the Federal Officer for Disability and the provincial child advocate offices.

Federal, provincial, and territorial collaboration to monitor coordination of care and support.

Given that the implementation and future reviews of the Act will be conducted in partnership with persons with disabilities, disabled persons organizations, and youth, it is imperative to include children who have not been previously represented in the process (e.g., children who are younger, have multiple disabilities, are from rural and Indigenous communities, and use nonverbal forms of communication etc). Their caregivers can serve as proxy-representatives but efforts should be made to include both the voices of children and their caregivers.

III. TESTIMONIALS FROM CHILDREN AND PARENTS OF CHILDREN WITH DISABILITIES

In this section, we present some examples brought by parents of children with disabilities and youth with disabilities in relation to several aspects that are meaningful for them in the context of services, policies, and participation in the community. The issues are presented as raised by them and in their own voices, showcasing examples of the extension of issues that impact the lives of Canadian children with disabilities and their families, and are not directly linked to all clusters presented in this report.

Establishing a Disability Advocate in Alberta

Alberta was one of the first provinces to establish an advocate for persons with disabilities. Public consultations (Albertans with disabilities, families, service providers, community organizations) were held to identify the role and responsibilities of the advocate:

“One of the biggest changes here in Alberta was the installation of the role of the provincial Disability Advocate. He reports to the Minister of Community and Social Services, creating an intersectional link between childhood support programs and disability. This is a program that has not been repeated elsewhere within Canada. Short of filing a human rights complaint, this is an office that identifies needs in any age bracket, however it’s currently one of two outlets to support child access to education and supports. The other being Inclusion Alberta.”

Rachel Martens

Parent advocacy through collaborations with community organizations

“The development of trust between those with lived experience and the organizations with a mandate to support them work well when they come together with common goals in advocacy. Which is one reason why I joined the

Calgary Ability Network. It's a place where we can identify needs as my current focus as a mother is in gaps in supporting disabled children's rights. This network has served as a space to discuss advocacy priorities in a coalition capacity."

Rachel Martens

Areas of Opportunity

Shift in Attitudes in Leadership

"A shift in attitudes in leadership towards investment in these policies rather than a charitable viewpoint would mean regular review measuring success of policies meant to support inclusion and participation. As things stand, not all provinces participate in the UN reporting process which would have them participate in review via the Special Rapporteur. And yet in my connections with leadership I have been told on numerous occasions that they stand by the efforts they have made in regards to access and support but have no data. I live in a province that right now is exercising fiscal restraint which means they are cutting early intervention funding by two years for children with disabilities. It makes it challenging to feel like ideal steps are being taken. The evidence points towards successes in early supports. It hurts to see as a parent."

Rachel Martens

Medical Assistance and Dying in Canada: Children with Disabilities & Ableism

"Current discussions on medical assistance in dying (MAID) in Canada generally ignore how the regulations will affect children with disabilities, including newborns in neonatal intensive care units (NICU) across the country. I am a PhD Student in Health Policy & Equity at York University. My research focuses on the lived experiences of People with Disabilities in relation to MAID and how it is impacted by access to home care, palliative care, and pain management in Canada. I'm also the mother of two beautiful boys - one with severe disabilities and one without. My boys have shown the world how beautiful disability is and that living differently is okay. Our experience of disability is filled with stigma, discrimination, and ableism. My amazing and beautiful son Kian has severe disabilities - doctors wanted to terminate my pregnancy and later wanted to withdraw care from him in the NICU. Through my advocacy, my research, and my community of families with children with disabilities, I have met many incredible children with severe disabilities- children who have wonderful lives and want to live. How doctors, professionals, government, communities and families treat people with disabilities is based on whether or not we have the resources to support them and whether or not we decide their lives are meaningful. There are many brilliant people with disabilities who have made huge contributions to society, including the likes of Stevie Wonder (Blindness), Stephen Hawking (Amyotrophic Lateral Sclerosis – ALS), Helen Keller (Hearing impaired and blindness), and Greta Thunberg (Asperger). If MAID is legalized for people who are not nearing death, what options will parents be given? How will doctors respond to babies and children with disabilities? In a world designed for the able bodied there are an incredible amount of hurdles that people with disabilities need to overcome. Instead of making death an option, wouldn't it be better to remove those hurdles?"

Samadhi Mora Severino

Accessibility

"I am frustrated when I can't go in places where I want to go with my wheelchair" (Youth, 16 years old). An accessible Canada for children and youth with disabilities is one that allows for children to make choices about where, with whom, and what they want to do and that regardless of where they are. For more child testimonials and report on a study about children's rights on the perspective of children refer to:

https://www.childhooddisability.ca/wp-content/uploads/2018/07/PolicyBrief_Spring2018.pdf

IV. CONCLUSIONS

The present alternative report addresses aspects related to the clusters 1, 5, 6, and 7 from the last Concluding Observations and Canadian Report to the UN Convention on the Rights of the Child. We present issues and research evidence focusing on different aspects related to the health of children with disabilities. These issues include: data collection, implementation and monitoring, health services, provision of assistive devices, the right to play and rest, and participation in the community. We also emphasize the importance of leveraging existing initiatives and policies such as the Accessible Canada Act, and the National Autism Strategies to improve the quality of life and promotion of rights for Canadian Children with Disabilities within National policies. This report does not present aspects related to the Education of children with disabilities in Canada, which is an important area that has been highlighted in the concluding observations and has not been fully addressed in the Canadian government report. The report also does not address the details of the important area of transition of children from child-based to adult-based services, another important area compromising child's ability to enjoy full citizenship.

We present some important considerations for implementation, based on research and on the testimonials of children and youth, as well as parents of children with disabilities. A summary of key suggested recommendations include: the application of a Children's Rights Impact Assessment within the Accessible Canada Act, the coordination of monitoring and implementation mechanism within the CRC and the CRPD including research support and active participation of children and families in the process; the establishment of data collection mechanisms that include administrative, disaggregated data by disability, and longitudinal data collection focusing on outcomes that are important for children and families such as participation in the community, active living, quality of life, inclusion and accessibility; leveraging on key national research and community initiatives to strengthen the childhood disability community in Canada in key areas such as play and health promotion; facilitating the exchange of best practices and positive outcomes among provinces and territories in key aspects such as the offer of aids and supports for mobility and communication, the supports offered in educational and health and rehabilitation services; and to bring diverse groups of organizations, researchers, service providers, families, children and youth towards a national disability strategy that focus on improving services, supports, and outcomes across jurisdictions and different areas such as education, health, community integration and welfare.

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VI. ANNEX A

LIST OF RECOMMENDATIONS

Cluster 1: General Measures of Implementation

Strengthen and update the evidence-base to inform policy, planning, and decision making by improving disability data collection:

Ensure data is collected on various aspects of children's lives such as: enrolment of children with disabilities in schools, proportion of staff trained and involved in disability and child-related programs, poverty indicators, living and housing conditions for children of all disability levels, number of children undergoing painful and invasive medical procedures, and healthcare expenditures.

Collect longitudinal data on experiences, outcomes, & impact of disability on both children and their families (WHO & the World Bank, 2011)

Collect data on young children with disabilities to guide service provision and social and policy systems (WHO & the World Bank, 2011)

Enhance psychometrics of data collection instruments (WHO & the World Bank, 2011)

Collect disaggregate data on disabilities (by type of disability) to contribute to the assessment of the current situation of children with disabilities and their families and to develop goals and programs based on real needs.

To establish a twin-track for monitoring and implementation of the CRPD and the CRC considering the specific needs of children with disabilities and their families

The Canadian Human Rights Commission, key partners in the civil society, representatives of different disability groups and children's rights groups (including groups in the disability and child rights that represent minorities within these groups such as indigenous, immigrants, refugees, LGTBQ2S) and academic researchers should convene a strategic planning. The goal should be to develop a twin-track approach that includes: CRC and CRPD indicators, common elements identified in previous reports for the CRC and CRPD, and concrete data being collected at the current Child Health Longitudinal Survey, research datasets, and administrative datasets related to education and social and community services to identify gaps in the realization of basic rights for children with disabilities, and propose solutions to be monitored in the next reporting cycle for both the CRC and the CRPD.

Cluster 5: Disability, Basic Health and Welfare

Governments across Canada should regulate and standardize the collection of data with respect to children with disabilities and the education, health, and welfare programs that support them, to ensure that data are consistent across jurisdictions and over time, and are comprehensive.

This will ensure that Canada can adequately evaluate realized access to disability programs for children with disabilities. This will allow Canada to determine whether government programs are adequately meeting the

needs of children with disabilities and their families, and, by extension, meeting the requirements under Article 23 of the UN CRC.

Improve equal funding allocation for families of a child with a disability:

Establish clear definitions of the different types of mobility devices, communication devices and other equipment and supports that are covered by provincial governments across the country.

Establish consensus on what is considered basic or essential use for mobility devices, communication devices and other equipment and supports (Smith et al., 2018)

Provide mobility funding to individuals with a disability “covered by the provincial or territorial health insurance program, regardless of age, residence, or health condition” (Smith et al., 2018)

Determine coverage and help choose the funding program based on assessed need as identified by the child, their families in collaboration with service providers (Smith et al., 2018)

Cluster 6: Education, Leisure, and Cultural Activities

To develop a Children’s Right Impact Assessment for the Accessible Canada Act and policies and standards developing from all the implementation process.

To use measures that are being developed in academic settings and community settings such as the Child Community Health and Inclusion Index (Eisenberg et al, 2015) to determine standards of accessibility for Canadian Children and consider children with disabilities unique needs in Canadian context to assess or benchmark actions and policies, including opportunities for consultation with children and youth with disabilities and their families.

To include child factors within accessibility monitoring and implementation planning.

To create mechanisms that coordinate programs nationally in aspects related to inclusion, accessibility, and health promotion opportunities including contextual factors and a variety of environments where children live such as educational settings, community settings, and health sector towards a common goal of promoting the right to play broadly.

Action should be done towards developing, implementing, and monitoring the effectiveness of policies and guidelines on inclusive play spaces to support participation of children with disabilities in play.

Cluster 7: Special Protection Measures (Inclusive policies and provisions)

Strengthen and update the evidence-base to inform policy, planning, and decision making by improving disability data collection across all childhood disability groups and not only autism.

Benchmark best practices and exchange information about outcomes of different provincial and territorial services

Facilitate consultations for high need areas (e.g. remote and Indigenous populations)

Pan-Canadian surveillance data for resource planning

Amendments to the Accessible Canada Act must be made to identify how the Act applies to children. That is, special provisions and considerations should be made for children and youth as the new legislation gets implemented at the federal and provincial levels. Considerations can include coherent, regulated, and monitored mechanisms of collaboration between the Federal Officer for Disability and the provincial child advocate offices.

Federal, provincial, and territorial collaboration to monitor coordination of care and support.

Given that the implementation and future reviews of the Act will be conducted in partnership with persons with disabilities, disabled persons organizations, and youth, it is imperative to include children who have not been previously represented in the process (e.g., children who are younger, have multiple disabilities, are from rural and Indigenous communities, and use nonverbal forms of communication etc). Their caregivers can serve as proxy-representatives but efforts should be made to include both the voices of children and their caregivers.