Participation and Knowledge Translation in Childhood Disabilities Lab-NGO-Canada-Session

Additional updates to the original alternative report:

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

March 01, 2020

Children with disabilities in Canada during the COVID-19 pandemic:

Additional information provided to the Alternative Report for the 5th/6th Review of Canada

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Submitted by the Participation and Knowledge Translation in Childhood Disability lab

to the United Nations Committee on the Rights of the Child

April 20th, 2022

The following updates reflect research-based data obtained in the context of multiple research projects conducted by different groups of Canadian researchers and stakeholders related to childhood disabilities and publicly available data related to Canadian children with disabilities and their families during the COVID-19 pandemic.

The different projects and authors for sets of information are acknowledged in each section

Nothing Without Us: Towards Inclusive, Equitable, COVID-19 Policy Responses for Youth with Disabilities and their Families

Authors: Jennifer Zwicker, Keiko Shikako, Anne Hudon, Chantal Camden, David Nicholas, Derrick Cogburn, Krystle Wittevrongel, Lucy Lach, Matthew Hunt, Mayada Elsabbagh, Raphael Lencucha, Sebastien Jodoin, Ash Seth, Brittany Finlay, Roberta Cardoso, Ananya Chandra, Anna Wiedmann, Kathy Li, Anna Katalifos, Sakiko Yamaguchi, Miriam Gonzalez, Samadhi Mora Severino

Children with Disabilities and their families are particularly vulnerable to the impacts of the COVID-19 pandemic. As a result, this population has a higher likelihood of adverse mental health outcomes from the COVID-19 pandemic. This is particularly concerning considering the high prevalence of pre-existing mental health conditions among youth with disabilities. There is a critical need to address mental health concerns in this population moving forward.

The Nothing without us is a research project funded by the Canadian Institues of Health Research designed to identify COVID-19 policy responses and identify pathways for more inclusive, equitable, and evidence-informed policies and programs to meet the mental health needs and promote well-being for Canadian youth with disabilities and their families.

The Government of Canada has pledged to ensure that mental health care is treated as a full and equal part of the universal health care system while “ensuring that health inequities are understood and addressed, including for Indigenous Peoples, Black Canadians and vulnerable Canadians.” In line with this, there is a need to understand the specific inequities faced by Canadian youth with NDD and their families during the COVID-19 pandemic, and how these inequities impacted their mental health. To bridge this gap, we engaged with Canadian youth with NDD and their families to learn about their experiences during the pandemic by: Conducting interviews with parents and caregivers of youth (age 0-30 years) with NDD, with youth with NDD (age 18-30), and collaborating with community groups and family partners.

The Global Report on Developmental Delays, Disorders and Disabilities-Canada.

Authors: Gonzalez, M., Yusuf, A., Steiman, M., Wright, N., Karpur, A., Shih, A., Shikako, K., & Elsabbagh, M.

This report was submitted to the Steering Group for the UNICEF and World Health Organization Global report on developmental delays, disorders and disabilities. The World Health Organization (WHO), in partnership with UNICEF and Autism Speaks, convened the Global Report on Developmental Delays, Disorders and Disabilities to document the lived experiences of caregivers of children with these conditions and thereby generate country-level data that can be used to inform advocacy, policy, and program planning efforts. A total of 883 caregivers of children and youth with disabilities (age 0-41 years) completed the survey.

Socio-demographic disparities in receipt of services during the COVID-19 pandemic for Canadian children with disability

Authors: Miriam Gonzalez, Jinan Zeidan, Jonathan Lai, Afiqah Yusuf, Nicola Wright, Mandy Steiman, Arun Karpur, Andy Shih, Mayada Elsabbagh, and Keiko Shikako

This studyexamined the relationship between socio-demographic factors and the receipt of health services (physical and mental health services) during COVID-19 for Canadian children with developmental disabilities.

Data collected in Canada for the Global Report on Developmental Delays, Disorders and Disabilities were used. The survey: (1) was developed and disseminated in collaboration with caregivers of children with disabilities, (2) included topics such as response to the pandemic and receipt of services and supports, and (3) documented the experiences of a non-random convenience sample of caregivers of children (any age) with these conditions during and prior to the pandemic. We used four logistic regression models to assess the association between socio-demographic factors and receipt of services.

Results from these studies demonstrated that most children with disabilities and their family members experienced significant mental health challenges during the pandemic. Specifically, participants reported increased anxiety, stress, feelings of sadness, loneliness, fear and worry. Key inequities that contributed to the mental health challenges experienced youth and families include:

Lack of ability to access disability services and supports consistently was detrimental to youth with NDD.

Lack of ability to access care and therapeutic services and education support for their children, as well as respite, compromised the capacity of parents and caregivers. Parents and caregivers were required to take on the role of educator and service provider to support their child’s health, learning and development, often without any external resources or support.

Mental health support was often inaccessible, unaffordable and/or unavailable. Many youth and parent participants expressed a desire to access mental health support during the pandemic but reported barriers with respect to a lack of available providers and an inability to pay.

Visitor restrictions in hospitals placed undue stress on families. Many youth with NDD require parents, caregivers and/or support persons to accompany them to the hospital.

Public spaces became inaccessible to youth with NDD and their families due to non-inclusive precautionary health measures and a lack of widespread recognition of exemptions.

Direct Health Impacts of COVID-19: Over one third (35%) of caregivers reported that they or someone in their home had gotten tested for COVID-19. About 6% reported that they or someone in their home had COVID-19.

Coping and Health: Over half of caregivers found it difficult to cope (e.g., keep a healthy lifestyle) or help the child with the disability cope (e.g., keep child's normal routine) during the pandemic. The majority of caregivers were worried about their health and the health of the child with the disability. Changes in their child's functioning were reported: sleep problems, mental health problems, and repetitive behaviours had worsened. Yet, a small group noticed some improvement in their child's functioning during the pandemic.

Access to Services, Information, and Supports: Accessing services and supports was challenging. Difficulties faced included: 1. Maintaining their formal and informal support networks 2. Receiving enough telehealth services for themselves and regular or telehealth services for their child. 3. Having financial or technical support to work from home 4. Getting schooling (daycare, pre-school, school) or educational plans for schooling their children at home 5. Figuring out available services/supports that were still available 6. Having COVID-19 information that was accessible for their children 7. Over a third of caregivers indicated it had been difficult to making enough money for essentials (over one third of caregivers reported it had been difficult to make enough money to get by).

Working less than full time, being a single parent, having low educational attainment (high school or less), having low income (making less than $40,000 per year), as well as male gender and older age of the child with disability were factors associated with decreased likelihood of receiving services.

When considering the period prior to the pandemic, caregivers reported challenges in:

1. Obtaining accurate information on how best to address the child's needs; 2. Accessing services to manage and support the needs of their child; 3. Accessing education for their child; and 4. Obtaining additional support for their child at school.

Analysing Canadian Policies during COVID-19: We used a text mining approach using the UN Convention on the Rights of Persons with disabilities to identify aspects of the provincial COVID-19 policies that related to children with disabilities and their families. Policies identified across provinces addressed mainly the articles related to the rights to Education, Emergency Preparedness Response, Home and Family, and Habilitation and Rehabilitation.

Canadian provincial Policies addressed the following areas:

Directions/Guidance to create safe environment for continuation of support services in health: alternative health care offers such as telehealth and rehabilitation

Education: distance learning alternatives and funding, return to school and precautionary measures

Housing : regulatory and precautionary measures related to group homes, family visit and access to home care

2) Availability of temporary financial support for families or for service providers (e.g. increased wage for home care workers in some provinces to facilitate access to this type of service for families)

3) Limited consideration of mental health supports and services, other than guidelines mentioning the need to pay attention to the mental health symptoms (anxiety, depression) for vulnerable populations such as children with disabilities

Stats Canada data

Authors: Rubab Arim, PhD, Leanne Findlay, PhD

New Data Collection Series during the COVID-19 pandemic: Canadian Perspectives Study Series (CPSS), Impacts of COVID-19 on Canadians: Data Collection Series, Other sources of data at Statistics Canada on child and youth health and disability: Canadian Health Survey on Children and Youth (CHSCY), Canadian Community Health Survey (CCHS), Canadian Survey on Disability (CSD)

Results:

From June 9 to June 22, 2020, over 32,000 participants voluntarily completed the online questionnaire that was designed to collect information from parents of children aged 0 to 14 about their concerns for their children and families as well as the activities of their children during the COVID19 pandemic.

Higher rates of concern among parents regarding their children’s health and education

Crowdsourcing participants were also asked about various concerns for their family. One notable difference was observed between parents of children with and without disabilities. Just over three quarters (76%) of parents of children with disabilities were very or extremely concerned about managing their children’s behaviours, stress levels, and anxiety and emotions compared with 57% of parents of children without disabilities.

A profile of children with affirmative responses to the 2016 census questions on difficulties with activities of daily living

Authors: Thomas Charters, Christoph Schimmele and Rubab Arim (https://doi.org/10.25318/36280001202200300006-eng)

The study examined data from the 2016 Census to establish a sociodemographic profile of children 0 to 14 years old as it relates to children’s difficulties with activities of daily living. The study explored activity limitations by children’s age, sex and household socioeconomic factors.

Results:

Approximately “13.5% of children had at least one activity limitation as a result of a difficulty or a long-term condition.”

Among the types of activity limitations, difficulty learning, remembering or concentrating was reported the most with 7.9% of children 0 to 14 years old experiencing it. It was followed by other health problems or conditions (4.0%), emotional, psychological or mental health conditions (4.0%), difficulty seeing (2.6%), difficulty with mobility, flexibility or dexterity (1.5%), and difficulty hearing (0.9%).

Sex and age: Boys were more likely than girls to experience activitiy limitations (15.5% of boys and 11.7% of girls). Older children were also more likely to have activitiy limitations than younger ones (5.3% of children aged 0 to 3 years and 20.7% of children aged 13 to 14 years).

Socioeconomic factors (SEF): Households where one or both parents had a university degree or diploma (10.4%), with two full-time employed parents in two-parent housesholds (11.7%), and households in the highest income quintile (10.7%) reported the lowest proportion of children with any activity limitation. The highest proportion of children with any activity limitation were reported in households where one or both parents had less than a secondary school education (17.1%), households with no working parents (19.2%), and in households in the lowest income quintile (16.4%). The study, however, cautions on the fact that causal associations between parental education, employment status and household income, and the likelihood of activity limitation should not be derived from these findings (i.e., low SEF cause activity limitations), as reverse causality is also possible (e.g., caring for a child with disability may limit the parent’s availability for employment opportunities).

Children from less affluent families and communities, particularly First Nations, Inuit and Black children, are disproportionately being left behind. The disruption in education during the COVID-19 pandemic has been widespread. However, it is very likely to disproportionately affect young people who were already at risk of disengagement from school, potentially lowering the rate of young people achieving basic proficiency and high school completion for years to come. The emergency reliance on online learning highlights a long-recognized equity gap – children of low-income families often lack access to highspeed internet, equipment, and support at home. There is also an urban-rural gap in broadband access. Children with disabilities and special learning needs are also less able to participate in virtual education without special support.

The Children First Canada. Raising Canada 2021: 10 Top Threats to Childhood in Canada - Recovering from The Impacts of Covid-19 also identified that poor mental health was an existing concern before the pandemic, and the effects of school closures have accelerated this threat. A key recommendation from this report was measuring what matters, by systematically collecting disaggregated national data on the health and well-being of kids across Canada, and particularly for children within intersectionality considerations such as children with disabilities, BIPOC and indigenous groups to measure progress and identify gaps and areas warranting attention.

Child Welfare, Mental Health, and Settler Colonialism: “Colonial violence and child welfare: Apprehension of BIPOC Children with Disabilities and from BIPOC Parents with Disabilities “

Author: Samadhi Moura Severino

Indigenous[2]children with Medical Complexity, those who need extensive and ongoing health services and supports, are often denied timely access to health care due to jurisdictional issues as a direct result of ongoing colonization (Blumenthal & Sinha, 2015). The right to access health care has taken a back seat to arguments over financial responsibility despite the introduction of Jordan’s Principle.

Indigenous children with disabilities who have status and are living on reserve are the financial responsibility of the federal government. If the same child lived off reserve, regardless of whether they have status, they are the financial responsibility of the provincial government (Blumenthal & Sinha, 2015; Palmater, 2014). There have been many disputes over which level of government is financially responsible for the health care of individual Indigenous Children with disabilities (Blackstock, 2016; Blumenthal & Sinha, 2015; Palmater, 2014).

The overlapping and contradictory structure of services for Status First Nations creates room for jurisdictional disputes. The federal and provincial governments have operationalized Jordan’s principle narrowly to limit its application for instance for First Nations child who has status or is eligible to have status is involved; resident on-reserve; a child assessed by health and social service professionals and has been found to have multiple disabilities requiring services from multiple providers; the assessment is made based on normative standards of care provided to similar children in a similar geographic location. (AANDC, 2013; FSIN, Government of Saskatchewan, & Government of Canada, 2009; Terms of Reference Officials Working Group, 2009 as cited in Blumenthal & Sinha, 201, p. 7).

Current legislative structures have prevented equitable policy outcomes and exacerbated health inequalities for Indigenous children with Medical Complexity because the current health care and legal system are deeply rooted within racist, ableist, and discriminatory ideologies (Palmater, 2014; Blackstock, 2016).

The federal government needs to stop underfunding Status Indians and address the large funding gap for health care and health services for Indigenous populations. Addressing this funding gap would allow Indigenous children with Medical Complexity to live at home with their families rather than being institutionalized for excessive periods of time due to financial disputes. It is equally important that the Canadian State applies the broad definition of the Jordan’s Principle because the current definition is violently disabling the bodies of these children through structural violence (Blackstock, 2016; Blumenthal & Sinha, 2015; Palmater, 2014; Erevelles, 2014; Galtung, 1969).

From these different sources of data, we can suggest a few key recommendations for Canada to address the needs of children with disabilities in the context of the UN CRC Article 23 and particularly in the design of policies and systems post-pandemic:

We recommend the government take a disability-inclusive approach to COVID-19 recovery and future emergency planning that considers the diverse range of needs within the childhood disability community.

Extensive consultations with a wide range of stakeholders, including disability service providers, representatives from non-profit and community organizations, self-advocates, and parents/caregivers.

Partnership with organizations and networks that have strong connections in the community and can help with scale and spread of programs that can meet needs

For example, Kids Brain Health Network has supported development of programs such as Social ABCs and Infant and Early Mental Health Hub for Training, Resources, and Tools that have flexible delivery models and a track record of successfully supporting youth with NDD

CHILD-BRIGHT network has a youth advisory board with individuals who have contributed to research and government consultations in different aspects and developed a Policy Hub and an infographic for families to understand their Human Rights and a system to combine research, families experiences and youth

Both networks along with Child Health Care Canada have collaborated in responding questions of families through the MyCOVIDQ social media campaign and other.

Cross-ministerial collaboration to co-design disability-inclusive strategies across sectors, particularly across health, education, and community services considering that many of the policies focused on service adaptations at school, but many children with disabilities receive their rehabilitation services through school, but were not able to access school during COVID-19 and even after schools were open many had specific health restrictions that limited their participation in in-person education and therefore limited their access to all the services that are offered through schools. Also community services such as respite care and individualized supports for children who require home care need to be planned in advance as families were left without the necessary supports to maintain functioning.

Ensure that existing and planned mental health investments including funding for mental health services that consider the unique mental wellness needs of youth with disabilities and their families, plan for programs to be delivered at school, at home and in the community:

The planned Canada Mental Health Transfer should specifically include funding for mental health programs for youth with NDD and their families

Existing service options such as Stepped Care 2.0 and Wellness Together Canada should include specific information for youth with NDD and their families

Create targeted services for families of children with disabilities, particularly low socioeconomic status families, indigenous children, BIPOC and other intersectionality during public health emergencies and in the continuation of services.

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