

## Project Name

*Nothing Without Us: COVID-19 Policy Responses to Improve the Mental Health of Youth with Disabilities and their Families*

## Document Objective

The purpose of this document is to create public awareness about the research project and engage stakeholders, decision makers and partners to ensure our work is addressing and informing issues concerning mental health for youth with disabilities and their families during the COVID-19 outbreak in Canada. To learn more about our work contact us at [youthstudiesinfo@gmail.com](mailto:youthstudiesinfo@gmail.com)

## What are the mental health implications of COVID-19 policy approaches for youth with disabilities and their families?

- Youth with disabilities, their families, and caregivers are at elevated risk from the COVID-19 pandemic and experience higher rates of mental health concerns [1, 2]
- Higher rates of underlying health conditions contribute to poor mental and physical health outcomes and a higher risk of contracting and getting infected by COVID-19 virus [3]. Persons with developmental delays are 5 times more likely to be infected with and 4 times more likely to die from COVID-19 than the general population [4, 5]
- Youth with disabilities and their families particularly those from low-income households, Indigenous Peoples and those residing in rural and remote areas face increased risk of mental health issues [6]
- Public health measures like physical distancing and mask-wearing taken to contain the spread of COVID-19 virus have exacerbated mental health issues as complying with these measures can be challenging for persons with disabilities [6]
- Ableist policies and service disruption has resulted in many mental health issues, including increased isolation, higher levels of anxiety, behavior changes, and sleep disturbances than relative to the pre-pandemic period [6]

## What are the gaps in knowledge around COVID-19 policy approaches for persons with disability?

- Addressing and mitigating the mental health issues as a consequence of non-inclusive COVID-19 policy approaches is critical for improving the health and well-being of persons with disabilities
- Aligning the pandemic response policies in the spirit of 'Nothing About Us Without Us'<sup>1</sup> and the *Accessible Canada Act*<sup>2</sup>, and in recognition of Canada's commitment to the United Nations Convention on the Rights of Persons with Disabilities (CRPD)<sup>3</sup> is critical to improve the health outcomes
- A disability-inclusive pandemic response requires that governments engage persons with disabilities and their families, assess their needs to match policy and community-based solutions, implement approaches to enhance persons with disabilities' capacity to cope with global health outbreaks and resulting mental health issues
- There is inconsistency in pandemic-related policy approaches taken across Canada to meet the unique mental health needs of persons with disabilities, and insufficient emergency preparedness planning and response
- This is particularly apparent for youth with disabilities and their families, as policy responses related to the youth are lacking across Canada further exacerbating mental health conditions
- Furthermore, there is a gap in learning from previous health emergencies to adapt policy responses [9] that address mental health needs of youth with disabilities and families

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<sup>1</sup> Nothing About Us Without Us is a principle mentioned by James Charlton that guides that people with disabilities should be at the centre of decision-making that concerns them.

<sup>2</sup> The Accessible Canada Act came into force on July 11, 2019. It is an act to ensure a barrier free Canada through the proactive identification, removal and prevention of barriers to accessibility wherever Canadians interact with areas under federal jurisdiction.

<sup>3</sup> The Convention on the Rights of Persons with Disabilities (CRPD) was adopted in 2006 at the United Nations. It is an international human rights treaty of the United Nations intended to protect the rights and dignity of persons with disabilities.

### What is being done to reduce the gap?

This knowledge gap means consideration of mental health needs and experiences of diverse youth with disabilities and their families may be lacking in the governments' pandemic response policies. To address this gap, our multidisciplinary research team and advisory council for the project is:

- Identifying and analyzing provincial, territorial, and national level COVID-19 related policies, and
- Determining the experiences of the youth with disabilities and their families during the COVID-19 pandemic to provide key insights into policy changes to improve the experience of youth with disabilities' during the pandemic

### How does this research project address the gap?

**Our team is identifying** COVID-19 policy measures implemented nationally and in each province and territory and their alignment with disability-inclusive policies that promote resilience and mental health. This will be accomplished by searching and identifying documents, such as research studies and policy briefs, that include disability-specific policies implemented in all provinces and territories across Canada. Using the UN CRPD as a framework to analyze and evaluate the inclusive policy measures we will be searching policy documents to understand how COVID-19 specific policy responses can impact mental health concerns for youth with disability and their caregivers. The search will focus on a range of policies such as:

- **Determination of essential services and accommodation:** Some of the responses include triage of essential medical services like ventilators, and implementation of preventive measures without accommodation for functional limitations [7, 8]
- **Access to supports and services like therapies, daily care, meals and medication, respite:** During the pandemic, many supports and services have been cancelled and families are faced with providing all care needs for their youth with a disability [1]. In addition, there could be challenges in accessing virtual services and support, such as access to technological devices, internet, data costs particularly in rural areas. Persons with neurodevelopmental disabilities may find the virtual health service disengaging than face to face interactions [6]
- **Access to information:** Limited plain language resources on COVID-19 guidelines, protocols and service delivery plans, make it difficult to access and navigate the information, and further exacerbate isolation and mental health issues [9]
- **Restrictions around quarantine and visitation policies:** Implementing no visitor policies during the beginning of COVID-19 outbreak at acute care settings and residential care homes restricted essential visitors like family members, or communication assistants for patients with disabilities impacted the decision-making abilities and health of persons with disabilities [7]
- **Disruption of social support and leisure activities:** The social and educational exclusion faced by young children with disabilities may be exacerbated under the current public health orders, with families and children unable to access services necessary for daily functioning [10]
- **Rights based issues in accessing services:** As Canada has rolled out vaccine distribution plans, persons with developmental disabilities and their families have been largely left out of this planning. Despite the current vaccine distribution recommendations prioritize some persons with developmental disabilities who reside in long term care facilities, most are not prioritized in spite of the evidence that the individuals represent a high-risk population [11]

We are also looking at how mental health needs and access to services have changed during the COVID-19 pandemic and how COVID-19 policies have impacted youth with disabilities and their families. We are currently conducting interviews with parents of youth with disabilities across all provinces and territories about their experiences during the COVID-19 pandemic. We are asking the participants about the ways in which they could have been better supported during the pandemic to provide insights into how COVID-19 policies can be better designed to meet the needs of Canadians with disabilities.

## Expected Outcomes

Findings from this work are aimed at providing evidence to inform decision-making and planning of pandemic-related policies. By working with the project's advisory council, our project's collaborative approach will facilitate rapid data collection and information to identify promising practices that better match disability inclusive policy approaches. If you are interested in engaging in the study, in our research to policy forum or learning more about findings from this study as they emerge, please contact us at [youthstudiesinfo@gmail.com](mailto:youthstudiesinfo@gmail.com) to join our mailing list.

## Acknowledgments

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## About the Team

The multidisciplinary research team and advisory council include persons with lived experience, knowledge users, community partners and experts in public policy, disability rights experts, mental health, disaster risk readiness, healthcare delivery, governance, ethics, global health and pandemic response analysis including the Canadian experience of the SARS pandemic and COVID-19 mental health knowledge synthesis.

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