



## EXECUTIVE SUMMARY

# Time to be Counted: COVID-19 and Intellectual and Developmental Disabilities

June 2021

*An RSC Policy Briefing*

The COVID-19 pandemic has impacted the lives and well-being of all people globally, with consequences being observed across all domains from physical and mental health to education and employment outcomes, to access to community supports and services. However, the disproportionate impact of the COVID-19 pandemic and its associated public health restrictions on individuals with intellectual and developmental disabilities (IDD) has largely been overlooked. Not only do people with IDD have a greater risk of severe complications and death from the virus as shown in large scale studies, but they also face significant short- and long-term consequences of COVID-related public health measures on their mental health and well-being.

At a time when this vulnerable population is already feeling undervalued, ignored, and forgotten, it is imperative that the risks facing adults and children with IDD – as well as their families and caregivers - are recognized, valued, and addressed through a disability-inclusive approach to Canada's pandemic policy response planning. This requires both a mainstreaming of disability inclusion into all COVID-19 response and recovery policies as well as disability-specific policies to address the unique barriers and challenges encountered by people with IDD during the pandemic. The recommendations in this policy briefing aim to achieve a more inclusive, accessible, and sustainable Canada for people with IDD both during and after the pandemic – an approach that will result in benefits for all of society.

### **Policy Recommendations**

In creating this Policy Briefing and the recommendations presented within it, several themes emerged which crossed several of the domains. In particular, two primary themes were identified as overarching principles that were used to guide the development of the domain-specific recommendations. These **guiding principles** (United Nations, 2020; Government of Canada, 2020) were:

- 1. "Nothing about us without us"** – the disability rights movement slogan which has been adopted by the United Nations Convention on the Rights of Persons with Disabilities and refers to the inclusion and active involvement of persons with disabilities in all pandemic response planning and decision-making that would impact them.
- 2. Accessibility and accommodations** – COVID-19 policies must incorporate the unique needs, challenges, and vulnerabilities of individuals with IDD, including equal access to COVID-19 testing, treatment, health care, and vaccination. All facilities and procedures must be accessible.

The domain-specific recommendations presented below and at the end of each relevant section were created in consideration of these principles and in response to the evidence reviewed in each domain, including any specific gaps in services and supports that were identified and agreed upon

by all co-authors as needs that must be addressed through further action. These recommended actions generally fall under the following themes: essential services and prioritization; accessibility of services; data collection and monitoring; funding needs; and information/guidance. In addition, the recommendations are targeted towards different agencies and government ministries at various levels (i.e. national, provincial/territorial, local) and in various domains (i.e. education, public health, social services) who are responsible for policies that affect persons with IDD in Canada. The themes and the specification of relevant stakeholders for each recommendation are more clearly laid out in the Appendix of the report. Finally, as described further in the Introduction and in the Appendix, the recommendations can also be divided into two types – both of which are essential components of a **disability-inclusive** approach: those that mainstream inclusion of persons with IDD in COVID-19 policy responses and those that address disability-specific considerations.

### **Summary List of Recommendations:**

**Recommendation 1:** Prioritize persons with IDD of all ages in the distribution of COVID-19 vaccinations in Canada along with other high risk clinical groups, in recognition of their heightened susceptibility to severe complications and death from the virus as well as the disproportionate impact of COVID-related public health measures on their health and well-being.

**Recommendation 2:** Ensure public health information and communication that addresses the health risks for children and adults with IDD is widely available and adheres to national accessibility standards.

**Recommendation 3:** Designate services, supports, therapy and support workers for persons with IDD as essential across health and social care sectors.

**Recommendation 4:** Provide health care accommodations for people with IDD both during the pandemic and post-pandemic recovery.

**Recommendation 5:** Use and adapt telehealth as needed in an accessible manner, to ensure functioning and well-being of individuals with IDD.

**Recommendation 6:** Allocate mental health services to address the unique needs of people with IDD and their caregivers who have been disproportionately impacted by the pandemic and ensure support for staff – including appropriate training and access to specialized mental health supports and resources.

**Recommendation 7:** Develop a data collection strategy of existing adapted and inclusive community programs, to identify community-specific gaps and needs.

**Recommendation 8:** Synthesize and promote an accessible resource and support guide with information on tools, virtual programs and approaches to promote health navigation, social support and leisure participation and inclusion opportunities for individuals with IDD and their families in local communities which would remain useful post pandemic.

**Recommendation 9:** Allocate additional funding for community-based participation initiatives for people with IDD to support innovative solutions that are sustainable post pandemic.

**Recommendation 10:** Ensure appropriate modifications, accommodations and supports are available to enhance the participation, development, and well-being of students with IDD both during and post-pandemic.

**Recommendation 11:** Monitor the long-term impacts of the pandemic on learning for students with IDD through individualized assessments.

**Recommendation 12:** Develop a National Disability Income Benefit sufficient to ensure a reasonable minimum income for all Canadians with a disability.

**Recommendation 13:** Design disability inclusive pandemic income supports. In addition, recognize persons with IDD and their families experience additional costs such as PPE for support staff and technology needs.

**Recommendation 14:** Enhance emergency caregiver benefits to family members or guardians of persons with IDD who are required to take leave from employment in order to provide care due to COVID-19 or similar pandemics.

**Recommendation 15:** Invest in post pandemic accessible employment support for people with IDD to support recovery from COVID-19 related job losses and reduced employment.

**Recommendation 16:** Ensure that guidelines and policies for residential care and congregate care settings are aligned with proposed long-term care standards and that unrestricted access of essential family caregivers to individuals with IDD be embedded in those standards and communicated transparently.

**Recommendation 17:** Collect, analyze and report surveillance data for people with IDD, including information on COVID-19 prevalence and outcomes for individuals with IDD in public settings, institutional and residential care settings.

**Recommendation 18:** Ensure continued access to resources for support staff and guarantee safe and affordable housing options for individuals with IDD through greater investment in community-based housing and supports to promote independent living.

**Recommendation 19:** Ensure that hospital triage protocols and guidelines are inclusive, equitable, transparent, and grounded in an ethical process that is based on human rights principles and informed by patients who would be affected by such protocols, including persons with IDD and their families. Health care providers involved in the critical care triage process must also receive training to reduce the risk of discriminatory bias.