

Kids Brain Health Network

Policy Brief: Impact of COVID-19 on children with neurodevelopmental disabilities and their families

“Most families raising a child with a neurodevelopmental disability were struggling prior to the COVID-19 pandemic. But what happened after was absolutely catastrophic. We can no longer afford to ignore the weaknesses in our systems of support.” – Dr. James Reynolds, Chief Scientific Officer, Kids Brain Health Network

“Things shut down overnight and supports literally evaporated. For families like ours you saw the difference immediately. We went from being reasonably okay, to crisis. While we’re in a much better place right now it took a very, very long time to rebuild that.” – Tracy, mother of multiple children with neurodevelopmental disabilities

Families in crisis

The COVID-19 pandemic has exposed deep cracks in access to services and supports for the more than 400,000 children under 14 years old across Canada living with neurodevelopmental disabilities (NDDs) and their families. Parents already faced challenges navigating systems to access timely testing, treatments, interventions, and ongoing support for their children living with autism, cerebral palsy, fetal alcohol spectrum disorder and other brain-based disabilities. The pandemic catapulted these families into crisis, resulting in a significant number of family breakdowns. Many parents have been forced to give up custody of their children, as the child welfare system was the only solution presented to them to address increased aggression and dangerous behaviours resulting from pandemic stresses.

Action needed

Swift and intentional action is required by the federal government to include this vulnerable population in COVID-19 recovery plans. A disability-inclusive pandemic response could significantly reduce the risk of long-term health – particularly mental health – outcomes. If parents are left to struggle alone, the impact on Canada’s health, education and social services systems will be felt for decades.

KBHN poised to help

Kids Brain Health Network (KBHN) is an internationally recognized, evidence-based, multidisciplinary network dedicated to improving outcomes for children with neurodevelopmental disabilities and their families. KBHN identifies and supports the most promising research and turns it into practical interventions, useful tools and real solutions that families and professionals can use every day. KBHN is focused on breaking down barriers to care so that all children with neurodevelopmental disabilities can live their best lives.

During the pandemic, many KBHN-supported programs pivoted from in-person support to online formats, breaking down geographical barriers. As the federal government develops its COVID-19 recovery plans, KBHN is poised to help identify successful programs that can be scaled up and replicated across the country.

Key challenges that need to be addressed

Several studies supported by KBHN during the pandemic identified key challenges faced by Canadian children and youth with neurodevelopmental disabilities and their families due to COVID-19, including:

- **Inability to access disability services and supports** that help with their development, provide structure, and allow them to thrive in society. Losing access to services, often with an insufficient replacement or no replacement at all, has resulted in a regression of developmental progress that in some cases had taken years to achieve.
- **Increased aggression and challenging behaviours in many children, some of which were not present before the pandemic.** Multiple studies supported by KBHN have reported increases in the frequency of

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aggression by children and youth towards other family members during the pandemic. For example, the National Consortium on Aggression toward Family/Caregivers in Childhood and Adolescence found that 76% of respondents reported daily or weekly forms of aggression in their children and 55% considered the intensity of this behaviour an 8 out of 10 or higher. This has resulted in increased caregiver anxiety levels and family breakdowns. Without appropriate interventions, this segment of the population will consume far more social service resources than the general population in years to come.

- **Capacity of parents and caregivers was compromised as care, therapeutic services, education support, and respite were cancelled or delivered virtually.** 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. These new roles often led to increased stress and burnout, and decreased capacity to manage competing responsibilities. The inability to access respite was a major contributor to the mental health challenges parents and caregivers experienced.
- **Mental health support was often inaccessible, unaffordable and/or unavailable.** Many families reported barriers with respect to a lack of available providers and an inability to pay for mental health supports for themselves or their children during the pandemic. Parents also found it challenging to find mental health services to meet their child’s unique needs, such as kids with communication challenges.
 - Children and youth with NDDs already experienced a higher frequency and severity of mental health issues compared to the neurotypical population before the pandemic.
 - COVID-19 exacerbated these pre-existing mental health issues, resulting in increased anxiety, stress, depression, self-harm, and poor functioning among this vulnerable population.
- **Public spaces became inaccessible to youth with NDDs and their families due to non-inclusive precautionary health measures and a lack of widespread recognition of exemptions.** Mask-wearing requirements were a source of stress, particularly for those with associated sensory issues. Plastic barriers introduced to help stop the spread of COVID-19 presented accessibility challenges for those in wheelchairs or with mobility issues.

Policy recommendations

To mitigate the mental health impacts on this population, a disability-inclusive approach to COVID-19 recovery and future emergency planning is required, including:

1. Ensure that existing and planned mental health investments, including funding for mental health services, are geared towards the unique needs of children and youth with NDDs and their families:
 - The planned Canada Mental Health Transfer should specifically include funding for mental health programs for children and youth with NDDs and their families.
 - Existing service options such as Stepped Care 2.0 and Wellness Together Canada should include specific information for children and youth with NDDs and their families.
2. Expand the Connecting Families Program designed to bring high-speed internet to families in need, specifically low- and middle-income families with children who have a neurodevelopmental disability. This is more crucial than ever, given the move to virtual services and supports.
3. Expand the National Autism Strategy to include people with other neurodevelopmental conditions as they face similar issues and challenges.

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4. Consolidate results from extensive consultations that have taken place with disability service providers, non-profit and community organizations, self-advocates, and parents/caregivers. KBHN could synthesize this information based on its own work and research currently underway through more than 70 CIHR grants to examine the impact of COVID-19 on children.
5. Establish an expert advisory group so rapid consultation around the needs of children with NDDs and their families can occur in future emergency situations.
6. Fulfill the promise to create a Canada Disability Benefit that augments the current Disability Tax Credit.
7. Facilitate cross-ministerial collaboration to co-design disability-inclusive strategies across sectors and include disability supports and services as essential services.
8. Support and partner with Kids Brain Health Network, which has strong connections in the neurodevelopmental disability community and can help with the scale and spread of evidence-based programs. In 2020, KBHN was renewed for a third and final cycle of funding under the Networks of Centres of Excellence (NCE) program. The NCE program will be phased out by 2024. KBHN is currently seeking support from the federal government's Strategic Science Fund (SSF) for \$51M over 5 years and is committed to ensuring that children, youth and families have access to the best supports and services no matter where they live.

Kids Brain Health Network (KBHN) is the first national research network in Canada to address the needs of children with neurodevelopmental disabilities. Since 2010, KBHN has invested more than \$60 million in over 150 programs that focus on early identification, early intervention and family support.

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