

Policy Brief: Disability inclusive policy to meet the needs of children with neurodevelopmental disabilities and their families

Pre-Pandemic – A Difficult Situation

Kids with neurodevelopmental disabilities and their families face barriers and challenges in everyday activities such as eating, communicating, sleeping, playing and learning. Parents and families often experience financial hardship, and live with the stress and isolation of finding, navigating, and accessing services and supports for themselves and their children.

Prior to the pandemic, children with neurodevelopmental disabilities (NDD) and their families faced a higher risk of adverse mental health problems and poor health and socio-economic outcomes. UNICEF, WHO and Royal Society of Canada reports have all discussed mounting mental health concerns for this population. Some examples include:

- Increased anxiety, stress, depression, self-harm, and poor functioning, particularly among those with pre-existing mental health issues.
- Increase in caregiver anxiety levels, primarily due to behaviour changes in their children and overall exhaustion from an increase in caretaking responsibilities.

COVID-19 Families in Crisis

“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

The COVID-19 pandemic 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 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 disorders. The pandemic catapulted families into crisis, resulting in a significant number of family breakdowns.

Swift and intentional disability inclusive action is required by the federal government to include children with disability and their families in child policy planning, emergency preparedness planning and COVID-19 recovery plans. A disability-inclusive approach to child policy and programs will significantly reduce the risk of long-term health – particularly mental health – outcomes. If children and parents are left to struggle alone, the impact on Canada’s health, education and social services systems will be felt for decades.

Solutions Exist, But Aren’t Reaching Families

There is much more to do to ensure that every child with a neurodevelopmental disability receives the support they need to reduce barriers and to thrive. Innovations and advancements in core challenge areas present opportunities to enable reaching the full potential for healthier kids, healthier families, and social and economic benefits to Canada.

Three Core Challenges:

- **Early Identification:** Evidence based early screening tools are needed to identify children at risk of a neurodevelopmental disability. With early identification, evidence-based interventions and supports can be harnessed in the critical early years for optimal brain development.

- **Access to Interventions:** Evidence-based interventions for neurodevelopmental disabilities are not progressing quickly enough into practice and/or are not being scaled in an accessible manner in all parts of the country or to diverse cultures and communities where there is a demonstrated need. Losing access to services during the COVID-19 pandemic, often with an insufficient replacement or no replacement at all, resulted in a regression of developmental progress that in some cases took years to achieve.
- **Family Support:** The supports for children living with neurodevelopmental disabilities and their families are fragmented and inadequate. This creates increased parental stress and anxiety, a disproportionate negative impact on the ability of caregivers (particularly mothers) to participate in the workforce, and a negative impact on the quality of life for both children and families.

Recommendations

We recommend the government take a disability-inclusive approach to child policy in the following areas:

1. **The government should fulfill the commitments it has made in the United Nations Convention on the Rights of Persons with Disabilities (UNCRPD).** There is an urgent need to apply a disability inclusive perspective to government policies and programs and implement evidence-informed innovative supports and services to better meet the needs of **all children**, including those with neurodevelopmental disabilities and their families. With the implementation of national accessibility legislation - the Accessible Canada Act (ACA) - Canada is committed to furthering the rights of children and youth with disabilities and realizing a barrier-free Canada by 2040.
 - Consolidate extensive child cross sectoral consultation from a wide range of stakeholders, such as disability service providers, representatives from non-profit and community organizations, self-advocates, and parents/caregivers.
 - Cross-ministerial collaboration to co-design disability-inclusive strategies across sectors.
2. Multiple studies supported by the Kids Brain Health Network have revealed an increase in aggression and challenging behaviours in children with NDD that have been exacerbated by the pandemic. For example, a study by the National Consortium on Aggression towards Family and Caregivers in Childhood and Adolescence found that 76% of respondents reported daily or weekly forms of aggression in their children and 55% considered intensity of behaviour an 8 out of 10 or higher.
 - Partner with organizations and networks that have strong connections in the community and can help with scale and spread of evidence-based programs.
3. It is well established that the frequency and severity of mental health concerns is far greater for children and youth with NDD compared with the neurotypical population, and that this disparity was again exacerbated by the pandemic. These children and their families will be the biggest consumers for most of the resources coming out of the pandemic. Canada must ensure that existing and planned mental health investments includes funding for mental health services geared towards the unique needs of children and youth with NDD and their families:
 - The planned Canada Mental Health Transfer should specifically include funding for mental health programs for children and youth with NDD 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 NDD and their families.
4. Mental health and other supports are often inaccessible, unaffordable and/or unavailable when and where they are most needed. Many families reported barriers with respect to a lack of available providers and an inability to pay for support. Parents also found it challenging to find mental health and other services to meet their child's unique needs. For example, one parent noted that many mental health professionals offer talk therapy, which is inaccessible to those with communication challenges.
 - Invest in disability inclusive supports and services.
 - 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.

5. Support networks such as the Kids Brain Health Network who are developing and translating evidence into practice, and working with partners to support children, youth and their families to have access to the best supports and services no matter where they live.
6. Expand the National Autism Strategy to be inclusive of other neurodevelopmental disability populations that experience many of the same issues and challenges.

Who We Are - Kids Brain Health Network

The Kids Brain Health Network (KBHN) is a national network that develops and harnesses scientific advances in technologies, interventions and supports with the goal of helping children with neurodevelopmental disabilities and their families live the best lives. The science of children's brain health is making advancements and KBHN is bridging the gaps between these scientific advances and implementing solutions that directly address the needs of children and families. **Through catalyzing collective action across sectors, KBHN's mission is working to ensure optimal care and better outcomes for children with neurodevelopmental disabilities and their families.** In delivering on its mission, KBHN is advancing federal responsibilities and priorities aimed at building a healthier future for children and families, building a barrier-free country and accelerating the pace of implementation, scale and spread of research innovations to unleash their full potential for healthier kids, healthier families, and social and economic benefits to Canada.

How KBHN Helps

Focused on helping kids live their best lives and easing the burden for families, KBHN identifies and funds the most promising research in kids brain health, working alongside families and partners and an extensive network of experts. Bridging the gap between scientific discovery and the families who need it most, KBHN builds and adapts implementation, commercialization and engagement processes that accelerate the pace of innovation to impact. From identifying the issue, to putting the innovation into practice and scaling it, KBHN's approach catalyzes available evidence-based solutions, making them accessible to those who need them. KBHN research initiatives are making a real difference in accessing early identification, evidence-based interventions and services, and family support benefiting children and families. KBHN is a leader, enabler and facilitator of initiatives that give families hope and empowers parents and others with science-based tools to help kids learn and develop. KBHN is working in multiple areas that directly address Health Canada priorities:

Addressing issues of early identification

- KBHN supports the Indigenous Early Learning and Child Care (IELCC) Framework, which aims to reduce health inequities between Indigenous peoples and non-Indigenous Canadians and improve the delivery of child welfare and health care under Jordan's Principle to focus on the best interests of the child. KBHN has active partnerships with Indigenous communities and co-develops training resources and tools to improve service delivery and mental health. Our approach incorporates worldviews, values, rituals and parenting practices distinct to Indigenous communities in Canada. This approach also provides guidelines to help frontline workers who are non-Indigenous to build the sensitivity and aptitude they will need to deliver programs.

Addressing issues of access to services and supports that help with child development, provide structure, and allow children to thrive in society.

- KBHN fosters collaboration between academic, private, and charitable sectors and government partners to accelerate the pace of discovery and ultimately improve the health and quality of life of children with neurodevelopmental disabilities and their families. KBHN facilitates and enables partnership and collaboration across sectors in all its funding programs, advancing health care systems and policy by supporting the development of evidence-based health care policy, that is aligned with the principles of inclusion, accessibility, equity, sustainability, and affordability.

- KBHN expands access to community-based services for children and youth with developmental disabilities and spreads evidence-based and disability inclusive models of community mental health care and culturally appropriate interventions. KBHN is the only cross-sectoral national network with deep expertise in disability inclusive approaches. KBHN innovates and adapts implementation and commercialization processes to be an accelerator for expanded access and spread.
- Working in collaboration with families and stakeholders, KBHN is accelerating the development of the National Autism Strategy. KBHN supports research and training to shift evidence to inform the development, implementation and monitoring of this Strategy. KBHN's Policy Fellowship initiative will continue to be a key contributor to informing and implementing the National Autism Strategy.

Addressing the issue of support for families

- KBHN aims to reduce health inequalities and improve the physical and mental health of Canadians by improving knowledge, skills and health behaviours at individual and population levels, particularly in the areas of mental health, maternal and child health, Indigenous early child development, and specific populations who are more vulnerable. KBHN delivers family training programs and core competencies related to implementation, policy and knowledge mobilization, EDI, and family engagement in research. In enhancing skills and knowledge among researchers, family and community members, educators, front line practitioners, and healthcare providers, KBHN is building capacity in the broader community to be knowledge brokers.

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.

www.kidsbrainhealth.ca