



The Strength of Family and Connections

Reaching out to and supporting children and youth with disabilities and their families: COVID-19 Response & Recovery Guidance Note

Introduction

Across the country, people and communities are trying to keep children and youth safe and well during the COVID-19 pandemic. We should spare no effort to ensure that children and youth with disabilities and their families remain safely together and connected to the services they need.

Families who need the most help may be reluctant to reach out because of stigma or because they fear that letting agencies know they are struggling might lead to heavy-handed child welfare interventions. The intersections of disability, ableism and systemic racism further contribute to impoverishment, social isolation and trauma, putting families at increased risk of excessive state intervention.

Families are doing their very best to cope on their own, but emerging evidence confirms they are not doing well at all. COVID-19 risks increasing the number of children who come into care because their family is unable to meet their needs. Much can be done to help young people with disabilities, as well as their families and caregivers get through a difficult and frightening time.

Supportive efforts must include actions to address systemic discrimination faced by young families – Indigenous, Black and racialized families in particular – who have been disproportionately impacted by the COVID-19 pandemic.

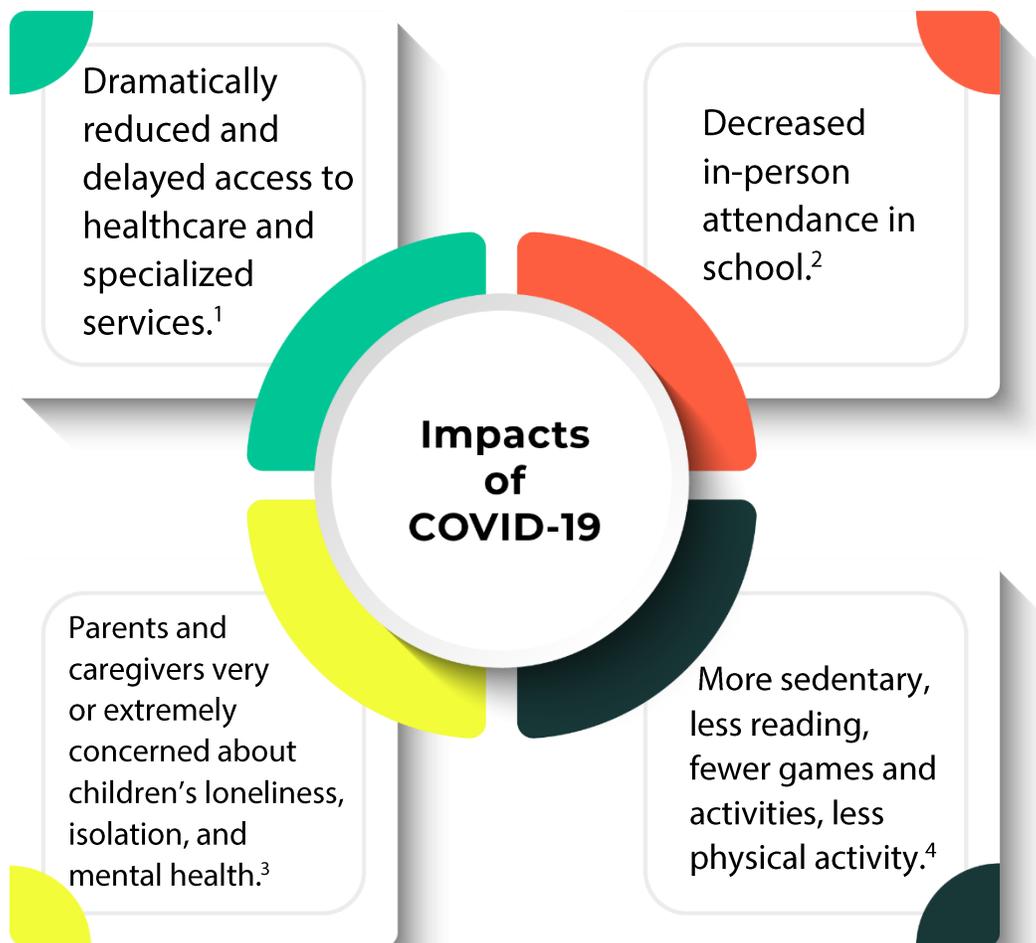
This publication provides guidance on how front-line practitioners, foster families, alternative caregivers, and governments can help create the conditions for hope and

love to shine through this difficult moment and into a brighter, more equitable future for all.

Impact of the Pandemic on Children and Youth with Disabilities and their Families

The COVID-19 pandemic has created a catastrophic crisis for children and youth with disabilities and their families. Therapies, specialized recreational programs, key health services, and respite care have been disrupted and delayed and young people in long-term care homes are separated from their caregivers for extended periods of time. These closures assume much more significance for families of children and youth with disabilities and complex medical needs. Inadequacies and inequities in the system have been amplified by the pandemic.

The prolonged, cumulative impact of the loss of social care infrastructure will not easily be reversed. Families who were already struggling to meet their needs and their children's needs are now having to manage in extraordinary circumstances. The fragmented social care infrastructure that existed has been pulled out from under their feet.



Supporting the Health, Safety and Well-Being of Children and Youth with Disabilities and their Families in the Context of COVID-19

We must be creative and determined in our efforts to protect, maintain and increase young people's and families' access to the services and supports that make up an essential social care infrastructure.

Social inclusion, equity and significant access to family, peers, community, culture and language must be maintained – the kind that satisfies the relational and emotional needs of the young person and those they are connecting to.

Trauma-Informed Approaches for COVID-19 Response and Recovery

The word trauma is used to describe experiences that cause intense physical and psychological stress. When we say that an approach is “trauma-informed”, we mean that it recognizes that people have experienced and have been affected by this trauma.

Families and children affected by different disability may have experienced some aspect of their life as traumatic – this may have to do with emergency visits, admissions to the intensive care unit (ICU), or interactions with service systems that have treated them in a manner that is traumatizing.

Trauma can also be historical and include colonisation, forced relocation, genocide, and racism. Historical and intergenerational trauma, caused by residential schools or by anti-Black racism for instance, can amplify the impact of other traumas.⁵

When supporting children and youth with disabilities and their families, start by recognizing that they, their families and communities may have experienced trauma and use a trauma-informed approach:⁶

- Start with the strengths of people and communities.
- Make sure people feel physically, psychologically, and culturally safe.
- Be trustworthy and transparent to ensure trust is built between those accessing services and those offering support.
- Value peer support, collaboration and mutuality – relationships are essential in healing from trauma.
- Give people and communities the power to decide how care and healing happens.

What Service Providers, Foster Families and Alternative Caregivers Can Do

- Involve and listen to children and youth with disabilities and their families when developing ways to help and support them. Build on their strengths, listen, and believe them when they tell you what they need.
- Be intentional in creating cultural safety.⁷ Seek to understand people's experiences, cultural background, connection, and identify and take into consideration cultural healing practices as part of the intervention plan.
- Use "person first" language and terminology that empowers and enables children and youth with disabilities.
- Recognize that those you are serving may have experienced trauma related to ableism and its intersections with anti-Indigenous and anti-Black racism:
 - Convey understanding and acceptance that racism and racial trauma exist.
 - Be open and curious and create a space for children and youth and their families to speak about race and how it shapes their experience.
 - Validate young people's worldview, their worth, and their strengths.⁸
- If you know a First Nations child or youth with disabilities who needs services and supports, Jordan's Principle may be able to help. Visit <https://fncaringsociety.com/jordans-principle> to learn more about Jordan River Anderson and Jordan's Principle.
- Intentionally and proactively check in and stay connected to families in any way you can. Provide opportunities for children and youth with disabilities and their families to connect virtually and in person, following local COVID-19 safety protocols. Do not wait for them to contact you.
- Pro-actively offer barrier-free financial help, services and emergency supports to strengthen families' ability to meet the needs of children and youth with disabilities.
- Commit to using whatever means at your disposal to report the extraordinary challenges and unmet needs you are seeing and hearing about to your employer and to government. Be a bold and engaged ally to families.
- Protect and promote the integrity of families when making decisions regarding children with disabilities in congregate living settings.

- Redeploy support workers to meet the needs of children and youth with disabilities and their families and ensure workers are trained on safety practices and protocols.
- Provide access to personal protective equipment (PPE) for support workers and to families who may be having other family members substituting as caregivers to support much needed respite.

What Governments Can Do

Provinces and territories can alleviate the significant financial and emotional stresses and the physical demands experienced by families of children and youth with disabilities in the following ways:

- Declare families of children and youth with disabilities essential workers and allow them to access critically important services and care for their loved ones during pandemic lockdowns.
- Include children and youth with disabilities, their families and essential service providers among groups prioritized for vaccines.
- Streamline approval processes for all funding streams and emergency benefits, to reduce paperwork for families and help them meet their children's needs.
- Provide easy access to free PPE as required.
- Provide flexible options for permanent and culture-affirming respite benefits for parents, foster families, and alternative caregivers, so that they may be emotionally and physically able to meet the demands of their children's care.
- Create flexible and responsive programs to help families and caregivers cover the full cost of culturally safe therapies, early intervention programs, positioning and mobility equipment, accessible vehicles, and housing – all of which are essential in preventing injuries and in promoting healthy development and community inclusion.
- Implement a flexible and comprehensive system of family caregiver pay for in-home caregiver supports that recognizes their essential role in the healthy development of children and youth with disabilities and the financial hardship and barriers to employment faced by families.
- Allow families to receive the federal Child Disability Benefit without clawing back the amount from social assistance.

- Ensure workers in health, social services, and child and family services receive training on developing and implementing disability-informed and trauma-informed policies, programs and services.

The federal government can address the significant financial stresses experienced by families of children and youth with disabilities in the following ways:

- Adopt the [Spirit Bear Plan](#) and end discrimination in public services for First Nations children, youth and families and extend [Jordan's Principle](#) beyond the age of 18.
- Include families and caregivers of children and youth with disabilities in the federal Disability Inclusion Plan and ensure the proposed Canada Disability Benefit is inclusive of such families.
- Immediately double the Child Disability Benefit and ask provinces and territories not to claw it back from social assistance.
- Examine and improve tax measures for people with disabilities:
 - Improve access to the Disability Tax Credit and Registered Disabilities Savings Plan.
 - Make the Disability Tax Credit refundable and extend compensation to people with the lowest income.
 - Provide additional refundable tax credits for families that are providing full-time care.
- Put in place a Guaranteed Livable Income, to meet the specific needs of families of children and youth with disabilities.

Protecting the Rights of Children with Disabilities

The Convention on the Rights of the Child (CRC)⁹ affirms the rights of children to have their best interests considered as a priority, taking into account all of their rights in decision-making that affects them (article 3). Many provisions recognize children's rights to the highest standard of health and rehabilitative care, to sustain or recover family relationships, to practice their language and culture, to education, to material security and social protection, to play and socialize, and to be heard when decisions affect them. Not only do children and youth with disabilities have all these rights, article 23 of the Convention affirms the right of a child with disabilities to "enjoy a full and decent life, in conditions which ensure dignity, promote self-reliance and facilitate the child's active

participation in the community.” They have rights to special care and assistance to achieve the fullest possible individual development and social integration.

In fact, article 7 of the Convention on the Rights of Persons with Disabilities (CRPD)¹⁰ provides that the state must “take all necessary measures to ensure the full enjoyment by children with disabilities of all human rights and fundamental freedoms on an equal basis with other children.” To help achieve this, article 23 affirms the right of children with disabilities to family life and support for families; article 24 provides for inclusive education; article 25 provides for equitable free or affordable, quality health services as well as specialized services that specifically meet the needs of children with disabilities; article 28 provides for an adequate standard of living as well as assistance for disability-related expenses including respite care; and article 30 provides for the right of children with disabilities to enjoy their culture on an equal basis.

The United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)¹¹ recognizes the “right of Indigenous families and communities to retain shared responsibility for the upbringing, training, education and well-being of their children, consistent with the rights of the child.” Article 14.3 of UNDRIP says, “States shall, in conjunction with indigenous peoples, take effective measures, in order for indigenous individuals, particularly children, including those living outside their communities, to have access, when possible, to an education in their own culture... provided in their own language.”

These rights are considered to be interrelated rather than a hierarchy of needs, which is why they need to be supported to the extent possible even when public health protection becomes a predominant consideration.

While some limits on the rights of children, youth and families may be necessary in a state of emergency – such as the COVID-19 pandemic – these restrictions must be reasonable, justifiable and based in judicious decision-making. All situations must be evaluated individually and any limits should be time bound, with regular review periods put in place to modify, ease or release restrictions as soon as possible. There should be exceptions made on a case-by-case basis where possible.¹²

Beyond respecting the rights of children and youth with disabilities, governments, agencies and caregivers must help them to feel safe and hopeful. That can only be facilitated by creating the conditions under which relationships and meaningful connections can be maintained and nurtured.

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¹ Bambusch, Jennifer; Lamden-Bennett, Shawna R.; Lloyd, Jennifer E. V. 2020. The Impact of COVID-19 on British Columbia's Children with Medical Complexity and their Families.

<https://open.library.ubc.ca/cIRcle/collections/facultyresearchandpublications/52383/items/1.0395118>.

² Bambusch et al. 2020.

³ Arim, Rubab, Findlay, Leane and Dafna Kohen. 2020. The impact of the COVID-19 pandemic on Canadian families of children with disabilities. <https://www150.statcan.gc.ca/n1/pub/45-28-0001/2020001/article/00066-eng.htm>.

⁴ Arim et al. 2020.

⁵ Fast, Elizabeth & Collin-Vezina, Delphine. 2010. Historical trauma, race-based trauma and resilience of Indigenous peoples: A literature review. *First Peoples Child & Family Review*. Vol 5:1, pp.126-136.

⁶ Substance Abuse and Mental Health Services Administration (SAMHSA). 2014. Guiding Principles of Trauma-Informed Care. SAMHSA Newsletter, 22:2.

https://www.samhsa.gov/samhsaNewsLetter/Volume_22_Number_2/trauma_tip/guiding_principles.html

⁷ Additional resources on cultural safety: <https://www.fnha.ca/wellness/cultural-humility>;

<https://www.heretohelp.bc.ca/visions/indigenous-people-vol11/what-indigenous-cultural-safety-and-why-should-i-care-about-it>

⁸ Kenneth V. Hardy, Healing the Hidden Wounds of Racial Trauma.

<https://static1.squarespace.com/static/545cdfcce4b0a64725b9f65a/t/54da3451e4b0ac9bd1d1cd30/1423586385564/Healing.pdf>.

⁹ United Nations Convention on the Rights of the Child.

<https://www.ohchr.org/en/professionalinterest/pages/crc.aspx>.

¹⁰ United Nation Convention on the Rights of Persons with Disabilities (CRPD)

<https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>.

¹¹ United Nations Declaration on the Rights of Indigenous Peoples.

http://www.un.org/esa/socdev/unpfii/documents/DRIPS_en.pdf.

¹² UNICEF. (April 9, 2020). Don't let children be the hidden victims of COVID-19 pandemic.

<https://www.unicef.org/press-releases/dont-let-children-be-hidden-victims-covid-19-pandemic>.