

CHILD-BRIGHT Members Share COVID-19 Concerns with Federal Disability Advisory Group Representative

Background

On April 30, 2020, as per the initiative of one of our patient-partners, a group of approximately 12 CHILD-BRIGHT representatives gathered for a virtual round table with Krista Carr, member of the federal COVID-19 Disability Advisory Group and Executive Vice-President of the Canadian Association for Community Living.

Purpose

To share with Krista Carr key concerns that she could bring back to the Federal Advisory Group in relation to children and families with brain-based developmental disabilities.

"This pandemic has reinforced what has been stated by many advocates previously, that where there were cracks in the system, they now feel more cavernous. Added to this as well is inequitable access to services across the provinces."

Round table attendee (parent)

List of Concerns

Immediate Concerns

- For children with disabilities who have other health needs (e.g., respiratory), there will be a need for long-term risk management while sheltering at home. This requires provincial and federal acknowledgement of the impact of the lack of income and education. The costs for providing this care for children with disabilities need to be considered alongside those for adult Canadians with disabilities;
- Parents' inability to be with their children in hospitals and long-term care homes;
- Inability to access or use Personal Protective Equipment (PPE).

Services

- Inability to access needed treatment/triage (services have been cut);
- Unequal access to online care services: most tele-health, tele-rehab, and online education AND leisure programs require parent/caregiver attention (if parents are working, these supports are compromised);
- Lack of mental health supports (phone or virtual are some alternatives);
- Absence of clear education plan for children with disabilities (e.g., need support aides);
- Lack of technology for education purposes (e.g., internet, devices);
- Lack of access to equipment and supports (personal, financial, and material) necessary to maintain rehabilitation, health, education, and leisure for their children.

Finances

- Additional financial burdens (income needs);
- Exclusion of persons with disabilities and their caregivers from the COVID-19 Emergency Benefit.

Data

- Lack of data on risks to children with disabilities (need to examine data on children to see what the risks are for children with disabilities);
- Lack of disaggregated data on the impacts of COVID-19 (this is needed to develop effective public health responses for children with various disabilities).

Suggested Actions

That these concerns be presented to the Federal Advisory Group.

COVID-19 response for children and youth with brain-based disabilities and families needs to be deliberate and purposeful. If not explicitly included in planning from the start or in budgeting or resource allocation, there is a risk that children with disabilities will be excluded from prevention, response aids, and follow up measures, despite facing heightened risks.

