

Access to Health Care and Coordination of Care for Children and Youth with Intellectual and Developmental Disabilities

Plain Language Version

Adopted November 2024

Children and youth should have equitable access to quality health¹ care that meets their needs as they grow. All levels of government need to make sure that children and youth with intellectual and developmental disabilities get the health care and support they need to live healthy, full lives. This means making sure that services and supports are coordinated and that children and youth get the right accommodations to participate fully in all aspects of community life, including child care and education.

People should have access to health care throughout their lives. This position statement focuses on the specific health care needs and calls to action for children and youth with intellectual and developmental disabilities.

Our position statement aims to change racist,² ableist,³ colonial⁴ and other unfair ideas about people with intellectual and developmental disabilities. Our goal is to promote the inclusion of everyone in the community, no matter how much money they have, where they come from (background or culture), what their religion is, if they are married or not, what their sex, sexual orientation, or gender identity and expression is, their age, or the type of disability they live with.

We recognize and support Indigenous rights and titles across British Columbia. We support the United Nations Declaration on the Rights of Indigenous Peoples, the 94 Calls to Action by the Truth and Reconciliation.

[Go directly to Calls to Action](#)

¹ "Health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity." - World Health Organization, online: <https://www.who.int/about/accountability/governance/constitution>

² Racist – discriminatory ideas against a person or group of people because they belong to a particular racial or ethnic group.

³ Ableist – discriminatory ideas against people with disabilities.

⁴ Colonial – ideas imposed from one group of people to another.

Background and Rights

Children and youth with intellectual and developmental disabilities often have complex health needs, including higher chances of other physical and mental health challenges. Despite increasing numbers of children with disabilities, we hear from families that fewer health care services and supports are available in their communities.

United Nations Conventions

Canada agreed to protect the rights of children under [The United Nations Convention on the Rights of the Child](#) in 1991. The treaty gives children with disabilities the right to access health and support services and requires Canada to make sure children have the right to the highest possible standard of health, including medical care. In 2010, Canada also signed the [United Nations Convention on the Rights of Persons with Disabilities](#) that says people with disabilities have the right to the best health care without discrimination.

In 2017, the Committee on the Rights of Persons with Disabilities raised concerns that people with disabilities face challenges in accessing healthcare facing physical, financial, and attitudinal barriers in [Canada's First Report](#). In 2023, the World Health Organization and UNICEF released a [Global Report](#) about children with developmental disabilities calling for more action to support children and families, including better care systems and more investment for health and inclusion towards children and youth.

Better access, strong oversight (people that make sure things are working), and updated health care services that meet the needs of children, youth, and their families are important for protecting rights, and improving health care in British Columbia.

The Need for a Comprehensive Pediatric Health Strategy

The Ministry of Health in B.C. acknowledges that health services for children and youth need to include people with disabilities. However, a lack of action has left gaps in care for young people with intellectual and developmental disabilities. We believe a **comprehensive strategy for children's health** should include:

1. Access to inclusive primary health care providers and specialists.
2. People get the health services and support they need when they need them.
3. A health care model that focuses on families, is inclusive of all children, and provides support, especially during transitions.
4. Different government ministries working together to help families find and use health care services and supports they need.
5. Full access to specialized services and medical equipment.

1. Access to inclusive primary health care providers and specialists.

Primary care providers are difficult to access and often can't support the everyday health needs of children and youth with disabilities. Doctors need to be better trained in medical school about these needs. Family doctors are turning away some families because their needs are too complex.

Many families struggle to find local doctors with the right knowledge about children with complex needs. They have to travel long distances to see pediatricians or specialized professionals, and this can be very expensive.

Mental health care is also hard to access for children with intellectual and developmental disabilities. We will address this in greater depth in our **Position Statement on Access to Mental Health for People with Intellectual and Developmental Disabilities**.

A better system should offer better care for children, youth, and families in their home communities with access to specialized health care teams that include

dietitians, nurses, pediatricians, mental health practitioners, speech-language therapists, occupational therapists, physiotherapists, adequate vision, hearing, and [dental care](#), navigators and coordinators of health care services, and health-based social workers.

A better system would bring health teams (including therapists and social workers) to local communities to support families and provide services close to home. This model is supported by projects like the [Slocan Redevelopment Project](#), with the goal of access to care across B.C., including in rural areas.

2. People get the health services and support they need when they need them.

Getting early assessments is important, but it's often delayed because of long waitlists and limited options. Many children start school without the therapies they need, and these supports can be very different from one school district to another. Some programs, like the [Early Intervention Program](#), [Autism funding](#), and the [At Home Program](#), stop offering services at certain ages or are only provided to children with certain diagnoses. Many children need help and are not getting it. Families with enough money can pay for privately for assessments and services, but there are many children and youth with intellectual and developmental disabilities with families who cannot afford to pay and are being left out.

There have been several reports explaining that children do not have equitable and adequate access to supports and services. All these reports have many recommendations that have not been fulfilled.

3. A health care model that focuses on families, is inclusive of all children, and provides support, especially during transitions.

Families often have to navigate a mix of different programs, especially during key transitions like starting school or moving to adult services. Missing a family-centered system can result in worse outcomes, such as needing emergency care or psychiatric help.

Difficult transitions for some families with children with disabilities start when they go from the hospital to home and when they are waiting for early intervention programs and trying to find inclusive child care. When children start school, it is another difficult transition when the child needs health support at school and in the after-school care.

[Research](#) has shown that the transition to adult services is one of the most difficult. Youth with intellectual and developmental disabilities are needing more psychiatric help, are given more medication or visit more often emergency rooms in hospitals.

A true child- and family-centered system would offer continuous support until age 25, giving families time to adjust to adult services and continue meeting their needs. Government ministries need to work better together and include families in the design of services and use the [guidelines for children care](#).

4. Different government ministries working together to help families find and use health care services and supports they need.

Healthcare can be hard for families to navigate because services are different in each area and between government ministries. It can be especially hard for families who are newcomers to Canada, Indigenous, members of the 2SLGBTQIA+ community, and families who live in rural and remote areas. The lack of coordination between ministries causes long delays and wait times for families. Programs like [Jordan's Principle](#), which are meant to improve access for Indigenous children, are often slowed down by these problems.

5. Full access to Specialized Services and Equipment.

Access to specialized health care services and medical equipment is not the same everywhere in B.C., with long waitlists because of a lack of funding and staff.

The At Home Program provides services like respite, medical equipment, medical supplies, medical travel and therapy supports for children with complex health needs. However, they can be difficult to access, are not coordinated, and families end up paying out-of-pocket for what they need.

The [Nursing Support Services](#) Program provides direct care for children with complex health needs in schools and respite for parents at home. There are more children who need these supports and not enough services for them.

Accessible housing and cars are also important for the health care needs of children at home and in their communities. These are very expensive, and many families go without them. This puts children and families at risk and creates barriers to get support at home and to go to medical appointments.

It is important we have a system where families can access what they need when they need it so that they have to rely on charities to get specialized services and medical equipment.

Calls to Action

The provincial government must take immediate action to improve access to health care and support for children and youth with intellectual and developmental disabilities.

- Make a focused investment in creating a **pediatric health strategy** that follows existing [guidelines](#) to meet the health needs of children and youth with intellectual and developmental disabilities fairly and quickly. This should include working across different government ministries to create an ongoing care approach as they grow.

To create a successful pediatric health strategy, key elements include:

- Create a **needs-based, family-centered, inclusive, and universal funding and service delivery model** to access health care and home care, including nursing support services and other specialized care support.
- Adequately fund **early and timely developmental assessments and diagnoses**, including genetic testing when needed.
- Create a strong process to **support the transition** from youth to adult health care that allows for a gradual transition and gives families time to connect with the adult health care system.

- Create a **plan to train, attract, and keep workers** in children's health services, which should include ways to:
 - **Attract and train more medical generalists and specialists** with knowledge about children and youth with intellectual and developmental disabilities in all B.C. regions, including better medical school training.
 - Create **community-based care coordination and navigation support programs** to help families find and use the health care services they need, using nurse navigators and health-based social workers, and making the system easier to use.
 - Build **home and community care support teams**, including therapists, specialized care aides, behaviour support professionals, support workers, and nursing support services.
- Develop **regional health strategies** that address the needs of rural and remote areas. This should include improving and growing outreach programs from BC Children's Hospital and building community teams to provide more local networks of support.
- Create a **needs-based access and funding model for medical equipment** (including assistive and communication technology), medical travel, medical supplies, speech therapy, occupational therapy, physiotherapy, mental health, and behaviour support for all children and youth who need these supports.
- Expand the **monitoring and reporting** work of the Representative for Children and Youth to cover health supports for children and youth.

Children and youth with intellectual and developmental disabilities must have all the support needed to realize their right to health. The United Nations Convention on the Rights of Persons with Disabilities recognizes that people have the right to enjoy the highest possible standard of health without discrimination on the basis of disability. We need decisive actions to build back and increase the capacity of the health care system from a place of abundance.

[Click here for our Position Statement on Access to Health and Coordination of Care for Adults with Intellectual and Developmental Disabilities, plain language version.](#)