

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

### Technical Version

Adopted November 2024

Children and youth should have equitable access to quality health<sup>1</sup> 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, ableist, colonial 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 Commission, and the B.C. Declaration on the Rights of Indigenous Peoples Act.

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<sup>1</sup> "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>

## Background

### Rights of children with intellectual and developmental disabilities

Children and youth with intellectual and developmental disabilities have unique, often more complex health needs and a greater presence of co-existing health and mental health challenges than their neuro-typical peers.<sup>2</sup> Despite the anticipated doubling of this population every 20 years and the evidence of co-existing health issues, we continue hearing from families that fewer community-based health care supports and services are available.

The [United Nations Convention on the Rights of the Child](#)<sup>3</sup> was ratified by Canada in 1991. [Article 23](#) says disabled children have the right to effective access to health and rehabilitation services. [Article 6](#) and [Article 24](#) collectively obligate the government of Canada to recognize the right of the child to life, survival, development, and the enjoyment of the highest attainable standard of health, including facilities for the treatment of illness and rehabilitation of health.

Canada ratified the [United Nations Convention on the Rights of Persons with Disabilities](#) in 2010.<sup>4</sup> [Article 25](#) says that persons with disabilities have the right to enjoy the highest attainable standard of health without discrimination on the basis of disability.

In its 2017 [concluding observations about Canada's first report](#),<sup>5</sup> the Committee on the Rights of Persons with Disability notes concern that people with disabilities continue to face physical, financial, and attitudinal barriers in accessing information and health care services.

In reviewing the human rights records of Canada, the 2023 [Report of the Working Group on the Universal Periodic Review](#) recommends to “fortify its existing policies

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<sup>2</sup> Liao, P, et al (2021). Prevalence and incidence of physical health conditions in people with intellectual disability – a systematic review, PLoS ONE 16(8): e0256294. <https://doi.org/10.1371/journal.pone.0256294>.

<sup>3</sup> United Nations Convention on the Rights of the Child, online: <https://www.ohchr.org/en/instruments-mechanisms/instruments/convention-rights-child>

<sup>4</sup> UN Convention on the Rights of Persons with Disabilities, online: <https://social.desa.un.org/issues/disability/crpd/convention-on-the-rights-of-persons-with-disabilities-articles>

<sup>5</sup> Committee on the Rights of Persons with Disabilities, Concluding Observations on the initial report of Canada, online: <https://docstore.ohchr.org/SelfServices/FilesHandler.ashx?enc=6QkG1d%2FPPRiCAqhKb7yhshFUYvCoX405cFaiGbrlB87R7e4hNB%2FgZKnTAU8BqK7FKCyFSQGUzS4dKwSRSD%2FCPUoSzW7oP9OI5lweGr%2Br%2B7wpRzQbCN1rv%2B%2BwMd4FofZ>

and augment investments geared towards ensuring the medical, psychological, social and economic well-being of persons with disabilities.”<sup>6</sup>

In 2023, the World Health Organization and UNICEF released the [Global Report on Children with Developmental Disabilities](#). It proposes priority actions to accelerate individual, family, community, and society-level changes to achieve inclusion and health equity. The report makes the case for greater investment and accountability, to build inclusive and responsive multi-sectoral care systems for children and youth with developmental disabilities.<sup>7</sup>

The Representative for Children and Youth plays a significant role in overseeing the children-serving system in B.C. yet lacks the mandate to provide advocacy support or to monitor health services delivered by the Ministry of Health. A recent statutory [Review of the Representative for Children and Youth Act](#) led to recommendations by the Select Standing Committee on Children and Youth, including “broadening the advocacy mandate to include Nursing Support Services and the assessment and diagnostic clinics for children with autism and complex behavioural disorders funded by the Ministry of Health or health authorities.”<sup>8</sup> This recommendation has not yet been implemented.

Improved access, strong oversight, and modernized health care services that are responsive to the individual needs of children, youth, and their families are essential in upholding rights, obligations, and strengthening health care for all British Columbians.

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<sup>6</sup> Report of the Working Group on the Universal Periodic Review-Canada (2023), online:

<https://documents.un.org/doc/undoc/gen/q23/251/73/pdf/q2325173.pdf> at 37,271

<sup>7</sup> WHO-UNICEF (2023), Global Report on Children with Developmental Disabilities

From the margins to the mainstream, online: <https://www.unicef.org/documents/global-report-children-developmental-disabilities>

<sup>8</sup> Select Standing Committee on Children and Youth (2023), Review of the Representative for Children and Youth Act, online:

[https://lims.leg.bc.ca/pcms/file/CommitteeDocuments/42nd-parliament/4th-session/cay/reports/CY\\_42-4-1-Report\\_Statutory-Review\\_2023-04-26.pdf](https://lims.leg.bc.ca/pcms/file/CommitteeDocuments/42nd-parliament/4th-session/cay/reports/CY_42-4-1-Report_Statutory-Review_2023-04-26.pdf) at p. 9-10.

## The need for a comprehensive pediatric health strategy

The [Service Plan for the Ministry of Health: 2023/24 - 2025/26](#) refers to the application of an **equity lens** for the design and delivery of health services and programs to embed cultural safety, anti-racism, and equity of Indigenous Peoples, immigrants, racialized groups, **persons with disabilities**, the 2SLGBTQIA+<sup>9</sup> community, and other populations who face systemic barriers.<sup>10</sup> Health services for children and youth need to be looked at in conjunction with disability-related services from the Ministry of Children and Family Development. This Ministry has acknowledged the barriers that children, youth and their families experience to inform its strategic direction in the [Ministry of Children and Family Development 2023/24-2025/26 Service Plan](#).<sup>11</sup>

Yet little to no action, collaboration, or investment has been made to ensure health care supports and services are accessible for children and youth with intellectual and developmental disabilities. We believe a **comprehensive pediatric health strategy** should include:

1. Secured access to community primary health care providers and specialized services.
2. Timely, equitable, and adequate access to health care supports and services.
3. A family-centered, inclusive, and universal model for accessing health care supports and services, particularly during transitions.
4. Coordinated initiatives across ministries to support the navigation and coordination of health care services.
5. Full access to specialized services and medical equipment to support the health care needs of children and youth.

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<sup>9</sup> 2SLGBTQIA+ stands for Two-Spirit, Lesbian, Gay, Bisexual, Transgender, Queer, Questioning, Intersex, Androgynous and Asexual.

<sup>10</sup> Ministry of Health (2023), 2023/24 – 2025/26 Service Plan, online:  
<https://www.bcbudget.gov.bc.ca/2023/sp/pdf/ministry/hlth.pdf>

<sup>11</sup> Ministry of Children and Family Development (2023), 2023/24 – 2025/26 Service Plan, online:  
<https://www.bcbudget.gov.bc.ca/2023/sp/pdf/ministry/cfd.pdf>, p.5.

## 1. Secured access to community primary health care providers and specialized services

Primary health care providers are difficult to access, lack specific expertise, and are not always available to support matters related to the everyday health needs of children with intellectual and developmental disabilities and complex health needs. Primary health care for this group of children and youth needs to be better addressed during medical school training. Some families are being turned away by primary care providers because their needs are too complex.

To have adequate health care, children with intellectual and developmental disabilities also need access to pediatricians and other medical specialists. However, these professionals are not readily available in many communities across the province, forcing families to travel to urban areas and incur significant expenses for transportation, accommodation, and care for their other children.

There is a growing awareness that mental health challenges frequently co-occur with intellectual disabilities, called dual diagnosis. Yet, we continue to see a lack of access to community mental health practitioners with specific expertise in the care of children and youth with dual diagnosis. We will address this in greater depth in our **Position Statement on Access to Mental Health for People with Intellectual and Developmental Disabilities**.

A modernized system of support should aim to better support 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](#),<sup>12</sup> navigators and coordinators of health care services, and health-based social workers.

An example is the [Slocan Redevelopment Project](#) which provides an opportunity to reimagine the system of support for children with both complex health needs and intellectual disabilities.<sup>13</sup> It has the potential to support an equitable, family-centered system of support across B.C., including rural and remote regions, that increases

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<sup>12</sup> Marquis, S. (2023), The Use of Medically Required Dental Services by Youth with Intellectual/Developmental Disabilities in British Columbia, Canada, J Can Dent Assoc, 89: n7.

<sup>13</sup> BC Children's Hospital, Slocan Site Redevelopment, online: <http://www.bcchildrens.ca/about/slocan>

regional capacity by building specialized community teams that are knowledgeable and responsive to the needs of children, youth, and families.

## 2. Timely, equitable, and adequate access to health care supports and services

Timely access to assessment, diagnosis, and developmental screening through infant development programs, pediatricians, and other specialists is critical. Delays in access to assessment and diagnostics further postpone vital therapies such as early intervention, including behaviour consultation and intervention, occupational therapy, speech therapy, and physiotherapy.<sup>14</sup>

We know that far too many children age out of [Early Intervention Therapy programs](#) and start kindergarten without receiving adequate services due to waitlists<sup>15</sup> and high caseloads. Once children begin school, there is a significant disparity between school districts in their approach to providing therapies. Some school districts offer all therapies, while others only offer consultation. In any scenario, the level of intervention that children need when they enter kindergarten or in subsequent years does not continue.

Lack of equitable and adequate access has been a well-defined and documented issue in recent years by multiple government-funded engagement processes, including the Select Standing Committee on Children and Youth 2019 [Report on Children and Youth with Neuro-Diverse Special Needs](#).<sup>16</sup> The Ministry of Children and Family Development, in the process of changing its service framework for children and youth with support needs, funded engagement and research and issued a [findings report](#) in 2019. The Representative for Children and Youth has released several reports, including [Left Out](#) (2020)<sup>17</sup> and the follow-up report [Still Left Out](#)

<sup>14</sup> Assessing & Supporting Your Child's Development, online: <https://www2.gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/assessing-child-development>.

<sup>15</sup> BC Association for Child Development and Intervention, BC's Specialized Children Services. Year in Review 20019-2020, p.6-10, online: [https://www.bccacdi.org/\\_files/ugd/7e6cfe\\_812698c7cadf413989f32ff4127cb0b4.pdf](https://www.bccacdi.org/_files/ugd/7e6cfe_812698c7cadf413989f32ff4127cb0b4.pdf).

<sup>16</sup> Select Standing committee on Children and Youth (2019), Children and Youth with Neuro-Diverse Special Needs, online: [https://lims.leg.bc.ca/pcms/file/CommitteeDocuments/41st-parliament/4th-session/cay/Report\\_SSC-CY\\_41-4-1\\_Neuro-Diverse-Special-Needs.pdf](https://lims.leg.bc.ca/pcms/file/CommitteeDocuments/41st-parliament/4th-session/cay/Report_SSC-CY_41-4-1_Neuro-Diverse-Special-Needs.pdf)

<sup>17</sup> Representative for Children and Youth (2020), Left Out: children and youth with disabilities in the pandemic, online: <https://rcybc.ca/reports-and-publications/cysn-report/>

(2023),<sup>18</sup> highlighting the cross-sectoral failures to provide equitable and timely access to support the health needs of children with disabilities in B.C.

Once an assessment or diagnosis determines a developmental delay or disability, children and youth must have access to ongoing supports and services that are individualized to their needs. However, common barriers to accessing the [Early Intervention Program](#), [Autism Funding](#), and the [At Home Program](#) include eligibility criteria and age limits. These criteria exclude many children, including those who require health supports. We address this in greater depth in our **Position Statement on Access to Supports and Services for Children and Youth with Intellectual and Developmental Disabilities**.

A [2023 report from First Call – Child & Youth Advocacy Society](#)<sup>19</sup> notes that families face financial inequities and other challenges when raising children with disabilities who require additional health care. Without equitable access, the system favours privileged families who privately pay for assessments to establish eligibility or use employee benefits to fund essential health supports. Meanwhile, other families struggle to meet their children's health needs, forcing many children to go without medically necessary supports.

### 3. A family-centered, inclusive, and universal model for accessing health care supports and services, particularly during transitions

Families are experiencing the negative impacts of not having a family-centered model of health care. Health systems for children and youth with intellectual and developmental disabilities and complex health needs are experienced as a patchwork of fragmented programs that are not family-centered. This is particularly evident at key transition points. Regional disparities and inequities in how programs are funded and delivered also prevent the system from truly meeting families' needs.

For children whose complex needs are revealed in the womb or at birth, the first transition is from hospital to home. Families find themselves in their home communities, navigating fragmented programs. Barriers include waitlists for early

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<sup>18</sup> Representative for Children and Youth (2023). Still Left Out: children and youth with disabilities in B.C., online: <https://rcybc.ca/reports-and-publications/reports/still-left-out/>

<sup>19</sup> First Call Child and Youth Advocacy Society (2023). Making Ends Meet, online: <https://firstcallbc.org/what-we-do/reports-and-research/making-ends-meet/>, p. 23.

intervention and inclusive child care, exclusion criteria for health-based support from the At Home Program and Nursing Support Services, and delays in diagnosis if disabilities are not identified at birth.

Similar challenges exist as children transition to kindergarten, when health support is required in the school setting, and for before- and after-school care. When the Early Intervention Programs were created, therapies were provided to children up to age 12. In the mid-1990s, these therapies were limited to age five because they would be available in schools as children entered kindergarten. However, these services are scarce and inconsistent across school districts. Families again experience difficulties around age 12, when children transition to the secondary school setting.

The transition to adult health services is increasingly challenging for families. "Life-course transitions have been identified as among the most difficult times for the health care of people with intellectual and developmental disabilities."<sup>20</sup> Across many health issues, youth with intellectual and developmental disabilities have worse experiences and outcomes than those without. During transitions to adult health care services, they experience an increase in psychiatric hospitalizations, medication use, and the use of Emergency Department services.<sup>21</sup>

It is concerning that some families feel pressured to put their children into government care to gain access to health supports and services or to ensure they will be prioritized for the adult system of health and home care support.<sup>22</sup> This is an indicator of the serious barriers and challenges faced.<sup>23</sup> We recommend the transition out of children's services be moved to age 25 to allow families time to connect with the adult system of health care services.

Historical efforts to improve the service model by moving programs from one ministry to another have not been successful, and a new approach is critical. Building a system that is child- and family-centered requires respecting and supporting

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<sup>20</sup> Marquis, S, et al. (2024). "Population Level Mental Health Diagnoses for Youth with Intellectual/Developmental Disabilities Compared to Youth without Intellectual/Developmental Disabilities," Research on Child and Adolescent Psychopathology, online: <https://doi.org/10.1007/s10802-024-01174-0>

<sup>21</sup> Marquis, S, et al. (2024). "Population level administrative data evidence of visits to the emergency department by youth with intellectual/developmental disabilities in BC, Canada," American Journal of Emergency Medicine, 69 (2023) 52-57, online: [10.1016/j.ajem.2023.04.006](https://doi.org/10.1016/j.ajem.2023.04.006)

<sup>22</sup> RCY, Still Left Out, supra note 18, p. 39.

<sup>23</sup> Baumbusch, Jennifer. (2023) "Commentary - Cliff or bridge: breaking up with the paediatric healthcare system," Paediatrics & Child Health, 2023 XX, 1-3, online: <https://doi.org/10.1093/pch/pxad061>



diverse family needs and choices, which would be better achieved through co-design with families and front-line professionals and following existing [guidelines](#).<sup>24</sup> Fulsome solutions to the cross-ministry issues are foundational to a successful system that truly works to meet the needs of children and their families.

#### 4. Coordinated initiatives across ministries to support the navigation and coordination of health care services.

Significant gaps in support exist between ministries and at key transition points, as well as disparities across provincial Health Authorities, School Districts, and Service Delivery Areas of the Ministry of Children and Family Development. We know that these are key contributors to children and youth being left without adequate access to disability-related health care supports. The systems that serve children and youth are difficult to navigate for all families but disproportionately affect people who are newcomers, racialized, Indigenous, 2SLGBTQIA+, and living in rural and remote areas. Front-line professionals also face challenges navigating the right resources at the right time in their efforts to support families. Care coordination support is needed along with a simplified system that is easier for families and professionals to navigate efficiently.

The Neonatal Intensive Care Unit team at BC Children's Hospital can attest to the gaps between ministries that often lead to children remaining in the hospital beyond the necessary discharge date while community and home-based support is being negotiated across ministries (At Home Program, Nursing Support Services, etc.).

Inter-ministerial discussions have been happening for years at the policy level. Yet, there have not been meaningful systemic changes. Children are left without supports and services for unreasonable periods of time, and access to support is fragmented across ministry silos. Programs like [Jordan's Principle](#),<sup>25</sup> show that jurisdictional issues are systemic problems and seek to make the system more immediately responsive. However, the lack of coordination at the provincial level has impacted the ability of Jordan's Principle to fulfill its demand in a timely manner,

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<sup>24</sup> Canadian Association of Paediatric Health Centres (2016) A Guideline for Transition from Paediatric to Adult Health Care for Youth with Special Health Care Needs: A National Approach, online: <https://www.childrenshealthcarecanada.ca/en/networks-and-hubs/Transition/Transition-resources/2017-05-10-CAPHC-Transition-to-Adult-HC-GuidelineV2F.pdf>

<sup>25</sup> Government of Canada, Submit a request under Jordan's Principle, online: <https://www.sac-isc.gc.ca/eng/1568396296543/1582657596387>

affecting, in turn, its purpose of preventing delays in accessing health care supports and services for Indigenous children and youth with disabilities.

Improving continuity, efficiency, and overall support for children and youth with intellectual and developmental disabilities can improve health and developmental outcomes while decreasing costs related to ineffective and inefficient services. Health care system transformation must be done in collaboration with all relevant ministries.

## 5. Full access to specialized services and medical equipment to support the health care needs of children and youth.

Access to developmental health services through [Infant Development Programs \(IDP\)](#), [Aboriginal Infant Development Programs](#), and [Early Intervention Therapy programs \(EIT\)](#) varies across the province, but waitlists are a common denominator due to underfunding and the resulting workforce challenges.

The Ministry of Children and Family Development is responsible for delivering many health-related supports to children with developmental disabilities under the At Home Program. These supports include respite, medical equipment, medical supplies, medical travel and therapy support. However, they are heavily gated and not well coordinated, leaving children and their families with unmet health care needs and significant out-of-pocket expenses. We will address this in more detail in our **Position Statement on Income Security for Families**.

[Nursing Support Services](#) is a Ministry of Health-funded program that trains support staff and provides direct care for children with complex health needs in schools and respite for parents at home. Nursing Support Services Coordinators have historically played an unofficial navigation and support role across B.C. for families of children with complex health needs. While the population continues to grow, more and more families are expressing that their care coordination needs are not being met.

The cross-ministry approach to providing medical equipment requires direct cross-sectoral interactions. For example, specialized positioning and mobility teams provide letters of justification for funding to the Ministry of Children and Family Development, which provides equipment under the At Home Program. These requests by health care professionals are often denied by the Children's Ministry

teams that do not have medical expertise. Families have no choice but to pay out-of-pocket, seek charity funding, or go without essential equipment.

Accessible housing and vehicles are important to meeting health care needs at home and in communities, but with hefty costs, families often go without them, creating daily health risks. This also creates barriers to professional home care support and attending medical appointments. The Ministry of Children and Family Development previously funded these through the Family Independence Fund and Children and Youth with Special Needs Fund,<sup>26</sup> but these funds collapsed in 2013, leaving a legacy of unmet needs.

Gaps in the health care system have been filled for years by non-profit organizations. It is important we build a system that includes timely access and does not leave families to rely on charitable organizations for access to critical specialized services and medical equipment.

## Calls to Action

The provincial government is responsible for improving access to health care and coordinating support for children and youth with intellectual and developmental disabilities and must act immediately to do so.

- Make a targeted investment in the development of a **pediatric health strategy** that utilizes existing [guideline recommendations](#)<sup>27</sup> to adequately meet the health needs of children and youth with intellectual and developmental disabilities in an **equitable and timely** manner with a focus on cross-ministry strategies to create an integrated care approach.

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

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<sup>26</sup> Canadian Institute for Inclusion and Citizenship (2014), Giving in Action Program Evaluation, online: <https://cic.arts.ubc.ca/giving-in-action-program-evaluation/>

<sup>27</sup> Canadian Association of Paediatric Health Centres (2018) Guideline for the Management of Medically Complex Children and Youth Through the Continuum of Care, online: [https://www.childrenshealthcarecanada.ca/en/networks-and-hubs/Complex-Care/CAPHC-National-Complex-Care-Guideline-2018\\_final.pdf](https://www.childrenshealthcarecanada.ca/en/networks-and-hubs/Complex-Care/CAPHC-National-Complex-Care-Guideline-2018_final.pdf)

- Create a **needs-based, family-centered, inclusive and universal service delivery and funding 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 diagnosis**, including genetic testing when indicated.
- 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.
- Establish a **workforce strategy** for training, recruitment, and retention in children's health services that includes strategies to:
  - **Attract and train more medical generalists and specialists** with expertise in health care for 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 for families](#)** building on existing research, including nurse navigators and health-based social workers, while streamlining services into a system that is easier to navigate.
  - 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 respond to the unique needs of rural and remote areas of the province. Assess and expand current BC Children's Hospital outreach programs and build community teams so children and youth can access more support closer to home.
- Create a **needs-based access and funding model for medical equipment** (including assistive and communication technology), medical travel, medical supplies, speech-language therapy, occupational therapy, physiotherapy, mental health, and behaviour support for all children and youth who require these supports.

- Expand the **monitoring and reporting** mandate of the Representative for Children and Youth to include 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 attainable 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, technical version.](#)