

# Toward Inclusion: The need to improve access to mental health services for children and youth with neurodevelopmental conditions

APRIL 2023



REPRESENTATIVE FOR  
CHILDREN AND YOUTH





April 5, 2023

The Honourable Raj Chouhan  
Speaker of the Legislative Assembly  
Suite 207, Parliament Buildings  
Victoria, B.C., V8V 1X4

Dear Mr. Speaker,

I have the honour of submitting the report *Toward Inclusion: The need to improve access to mental health services for children and youth with neurodevelopmental conditions* to the Legislative Assembly of British Columbia.

This report is prepared in accordance with Section 20 of the *Representative for Children and Youth Act* which gives the Representative authority to make special reports to the Legislative Assembly if the Representative considers it necessary.

Sincerely,



Dr. Jennifer Charlesworth  
Representative for Children and Youth

pc: Ms. Kate Ryan-Lloyd  
Clerk of the Legislative Assembly  
Ms. Karan Riarh  
Committee Clerk, Legislative Assembly

## Contributors

The Representative would like to acknowledge with gratitude all those who shared their perspectives and made this report possible, including Charlotte Waddell, Christine Schwartz, Jen Barican, Donna Yung, Ange Cullen and Daphne Gray-Grant at the Children's Health Policy Centre at Simon Fraser University, RCY Executive Lead Alan Markwart, and staff from RCY's Systemic Advocacy, First Nations, Métis and Inuit Research team, Communications and Reviews & Investigations teams.

This is the Representative for Children and Youth's report. Appended to this report is the report by the Children's Health Policy Centre, *Addressing Mental Health Needs for Children with Neurodevelopmental Conditions: A Research Report*.

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## **Territorial Acknowledgment**

The Representative and staff, who do their work throughout the province, would like to acknowledge that we are living and working with gratitude and respect on the traditional territories of the First Nations peoples of British Columbia. We specifically acknowledge and express our gratitude to the keepers of the lands on the traditional territories of the Lheidli T'enneh peoples (Prince George) and the Songhees and Esquimalt Nations (Victoria), where our offices are located.

We would also like to acknowledge our Métis and Inuit partners and friends living in these beautiful territories.

# Introduction

Since the Ministry of Children and Family Development (MCFD) announced the implementation of its Children and Youth with Support Needs<sup>1</sup> Framework (CYSN Framework) in October 2021,<sup>2</sup> the issue of services to children and youth with support needs has been the subject of much discourse amongst service providers, advocacy groups, the Legislative Assembly, Indigenous leadership, the media and, most importantly, the families of those children and youth. At that time, MCFD announced that four early-implementation Family Connections Centres (FCCs) would be established in two separate regions which would offer a range of services to children and families.<sup>3</sup> The FCC services were to be delivered based on assessed needs, rather than solely on diagnosis, and be offered to both a greater number and a broader range of children and youth with support needs. These early implementation service “hub” sites were to be followed by a rollout of FCCs throughout the province and the termination of individualized funding to families for autism services in 2025.

In response to significant concerns from a variety of fronts about the proposed new service model, the premier and MCFD minister announced a “reset” to the initial plan in November 2022. The reset involves maintaining individualized funding for autism services, including for children who are newly diagnosed; pausing the province-wide rollout of FCCs while proceeding with four (now) “pilot” FCC sites; consulting more deeply with parents and caregivers, First Nations, Indigenous peoples, communities, experts and practitioners, and other stakeholders with lived experience; co-creating a better system of supports with Indigenous communities; and, as the new system is being developed, investing in new interim services for “under-served populations” such as children and youth with fetal alcohol spectrum disorder (FASD), Down syndrome and other neurodevelopmental conditions.<sup>4</sup>

<sup>1</sup> MCFD has recently re-described services to “children and youth with special needs” – which is commonly understood – as “children and youth with support needs,” which is less commonly understood. Both are otherwise known as “CYSN.” Other descriptors include children and youth with “diverse needs,” “children with disabilities,” “neurodiverse” children and youth, “neurocognitive developmental conditions” or “neurodevelopmental conditions.” Although there is no one agreed-upon term, in this report, we will use the term “children and youth with support needs” to align with MCFD’s terminology. CYSN includes a broad spectrum of disabilities, including neurodevelopmental conditions, sensory impairments (e.g., deaf, blind) and physical disabilities (e.g., mobility). This report is limited to children and youth with neurodevelopmental conditions. The largest populations in this grouping include autism spectrum disorder (ASD), fetal alcohol spectrum disorder (FASD) and intellectual or developmental disability (ID or DD).

<sup>2</sup> Government of British Columbia, “Improved system coming for children and youth with support needs,” news release, Oct. 27, 2021 <https://news.gov.bc.ca/25607>.

<sup>3</sup> At the time of the announcement, the Family Connections Centres were referred to as “family connection hubs.” See Government of British Columbia, “Improved system coming for children and youth with support needs,” news release, Oct. 27, 2021, <https://news.gov.bc.ca/releases/2021CFD0067-002047>.

<sup>4</sup> Government of British Columbia, “Premier, minister commit to maintaining individualized autism funding, engaging in deeper consultation for a new funding and services model for children and youth with support needs,” news release, Nov. 25, 2022, <https://news.gov.bc.ca/27874>. BC’s *Budget and Fiscal Plan 2023/24 to 2025/25* allocates \$95 million over three years for interim investments for under-served populations and deeper consultations about funding and the service model for CYSN, see <https://www.bcbudget.gov.bc.ca/2023/default.htm>.

In response to the announced reset, amongst other matters, the Representative for Children and Youth (RCY) emphasized the need for inclusion, saying:

*“Every child with special needs has the right to enjoy the best possible life, and government has the responsibility to remove barriers so they can grow up supported and engaged in their community – including their social services supports.”<sup>5</sup>*

As will be discussed, the Representative has long advocated for reform of the system of services to children and youth with support needs so that services are based on assessed needs, rather than solely on diagnosis, and for the provision of the full range of necessary and appropriate services and supports so that the needs of the whole child can be addressed. As we shall see in this report, one of these pressing needs is accessible and appropriate mental health services; in particular, for children and youth with neurodevelopmental conditions, the largest populations of which include those with autism spectrum disorder (ASD), fetal alcohol spectrum disorder (FASD), and intellectual or developmental disability (ID or DD).<sup>6</sup> Removing current barriers and providing a fulsome and appropriate mental health service system for this distinct and highly vulnerable sub-population of children and youth is critical to better supporting community inclusion and must be included and appropriately resourced in the forthcoming redesign of the system – or systems – of services to children and youth with support needs.

### What do we mean by a whole child approach?

A “whole child” approach requires public services for children to consider and address the full range, and intersectionality, of the needs and circumstances of children and their families so that healthy development and well-being can be best supported and optimized. This demands an “all-of-government” approach to addressing the social determinants of health, such as income and food security, housing, early childhood development, education and literacy, social supports, access to health services including mental health services, and social inclusion. An all-of-government approach to the whole child therefore requires the engagement and coordination of several ministries, especially Social Development and Poverty Reduction, Housing, Children and Family Development, Education and Child Care, Health, and Mental Health and Addictions.

<sup>5</sup> Representative for Children and Youth, “Representative’s statement on services for children and youth with support needs,” Dec. 2, 2022, <https://rcybc.ca/wp-content/uploads/2022/12/Representatives-Statement-Dec-2-2022.pdf>.

<sup>6</sup> The appended Child Health Policy Centre (CHPC) report gives child and youth population prevalence rates of 0.4, 0.8 and 1.2 per cent of the child population for ASD, FASD and ID, respectively. It is important to note, however, that there are overlaps in estimates and therefore these figures are not additive. Children and youth with ASD or FASD may also be diagnosed with ID. For example, RCY’s *Excluded* report indicated that 25 per cent of the children and youth in the province who were diagnosed with FASD by health authority assessment clinics were also diagnosed with ID. Similarly, reviews have indicated that, among children with ASD, about one-third (35 per cent) also had ID. See <https://www.cdc.gov/ncbddd/autism/addm>. There also can be concurrent diagnoses of ASD and FASD.



**Autism spectrum disorder (ASD)** – The symptoms of ASD involve persistent deficits in social communication and social interaction across multiple contexts and restrictive, repetitive patterns of behaviour, interests or activities. These symptoms cause clinically significant impairment in social, occupational or other important areas of current functioning. Although autism can be diagnosed at any age, it is described as a developmental disorder because symptoms must be present in a child's early developmental period.

**Fetal alcohol spectrum disorder (FASD)** – FASD is a neurobehavioural disorder associated with prenatal alcohol exposure. Diagnosis requires confirmation of prenatal alcohol exposure together with assessed impairments in cognition, self-regulation and adaptive functioning.

**Intellectual disability (ID)** – ID is a condition that originates in a child's developmental period which involves significant impairments in intellectual functioning (such as learning, reasoning and problem solving) and in adaptive functioning skills (such as communications and social skills, personal independence and school functioning). Diagnosis typically requires an IQ below 70 but must also be based on clinical assessment of adaptive functioning.<sup>7</sup>

The impetus for this report flows from the daily exercise of the Representative's statutory functions to provide individual advocacy services to children, youth and their families, as well as to review reports of critical injuries and deaths of children and youth. The Representative sees far too many situations where mental health services for children and youth with neurodevelopmental conditions are not adequately provided or are not provided at all.<sup>8</sup>

This is the second in a series of research briefs the Representative has commissioned to better understand the prevalence, priorities and promising practices related to mental health and wellness for distinct populations of children and youth, including those in care, those with support needs, gender diverse youth, and Indigenous children and youth.<sup>9</sup> It is also the second report in the series in which the Representative has partnered with the Children's Health Policy Centre (CHPC) at Simon Fraser

<sup>7</sup> Descriptions of these conditions/diagnoses are brief summaries derived from: American Psychiatric Association, *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (Arlington, VA: American Psychiatric Association, 2013).

<sup>8</sup> In 2021/22, the Representative dealt with 1,795 individual advocacy requests involving 1,811 children, youth and young adults, and 2,516 in-mandate reports of critical injuries and deaths, some of whom are children and youth with support needs, including those with neurodevelopmental conditions. As will be discussed, the reports of critical injuries and deaths reflect only a small number of the CYSN population in receipt of government-funded services. RCY does not receive critical injury and death reports on children and youth with support needs unless there are concurrent services being provided under the *Child, Family and Community Service Act (CFCS Act)*, *Youth Justice Act*, or mental health or addiction services, and most CYSN are not concurrently involved with one of those services. Nonetheless, when a child or youth with support needs, including a neurodevelopmental condition, is concurrently involved in the child welfare system and there is a report of a critical injury or death, a review is undertaken which enables the Representative to ascertain whether there were diagnosed or suspected mental health concerns and the nature of the mental health services provided, if any. As well, RCY advocates typically immerse themselves in the day-to-day details of service delivery, which enables them to ascertain the involvement of mental health services and the adequacy of those services for children and youth with support needs who are in receipt of advocacy services.

<sup>9</sup> The first report was *A Parent's Responsibility: Government's obligation to improve the mental health outcomes of children in care* (Victoria, B.C.: Representative for Children and Youth), Sept. 20, 2022. <https://rcybc.ca/wp-content/uploads/2022/09/RCY-ParentsResponsibility-Sept2002.pdf>.

University to carry out a rigorous review of the scientific literature on this topic and produce a research report, appended, that tries to answer two key questions:

- What does the scientific literature tell us about the prevalence of co-occurring mental health disorders amongst children and youth with neurodevelopmental conditions, in particular those with ASD, FASD and ID?
- What programs and services are scientifically proven<sup>10</sup> to be effective in treating co-occurring mental health problems amongst children and youth with neurodevelopmental conditions?

A summary and discussion of the key findings and implications of the CHPC report are described below, including a review and discussion of policy and program planning responses to this issue by MCFD, which is responsible for both CYSN services and Child and Youth Mental Health (CYMH) services, and by the Ministry of Mental Health and Addictions (MMHA).<sup>11</sup> This will be prefaced by a review of previous reports on the issue of mental health services for children and youth in general – and for children and youth with neurodevelopmental conditions in particular – by the Representative and others, government’s responses to those reports, a description of current services and relevant RCY case information. To begin, however, the issue of mental health services for children and youth with neurodevelopmental conditions should be contextualized within the framework of the rights of these children and youth to health care, including mental health care, and government’s obligations to put in place the services necessary to support the realization of those rights.

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<sup>10</sup> It is noted that CHPC applies a rigorous Western scientific approach to determining effectiveness of interventions, which excludes interventions that are either delivered in the context of non-Western scientific approaches or have not (yet) been evaluated/measured and reported on in Western scientific literature. The Representative recognizes both the benefits and the weaknesses of the Western scientific approach and will address Indigenous perspectives and interventions for child and youth mental health and well-being in a future report in this series.

<sup>11</sup> MCFD is responsible for most CYSN services as well as CYMH services, the latter of which include community-based mental health services for children and youth, as well as the Maples Adolescent Treatment Centre and Youth Forensic Psychiatric Services. MMHA and the Ministry of Health (MoH) have responsibility in partnership with health authorities for some community-based mental health services that serve children and youth such as integrated child and youth teams, Foundry, Early Psychosis Intervention (EPI) Program, mental health crisis response teams, etc. Otherwise, health authorities are responsible for the provision of mental health hospital services such as are found at BC Children’s Hospital, Ledger House, the Carlisle Youth Concurrent Disorders Centre, and regional in-patient adolescent psychiatric units. Further, the Provincial Health Services Authority is now responsible for the Provincial Assessment Centre which is a specialized psychiatric stabilization and assessment unit for Community Living BC (CLBC) clients and which accepts some referrals of adolescents with support needs who will be eligible for CLBC services as adults, while MCFD contracts health authorities to provide specialized community-based Developmentally Disabled Mental Health Services (DDMHS) for youth who are developmentally disabled (DD) and have serious concurrent psychiatric problems.

## The Rights of Children and Youth with Support Needs

Simply put, according to international human rights instruments, children and youth generally – and children and youth with support needs as well as Indigenous children in particular – have a right to health care, including mental health care.

Article 24 of the *United Nations Convention on the Rights of the Child (UNCRC)*, which was ratified by Canada in 1991, requires that:

*“States parties recognize the right of the child to the enjoyment of the highest attainable degree of health ...”*<sup>12</sup> (emphasis added)

The World Health Organization defines “health” as “a state of complete physical, **mental** and social well-being and not merely the absence of disease or infirmity.”<sup>13</sup> (emphasis added)

As well, the *United Nations Declaration on the Rights of Indigenous Peoples (UNDRIP)*, the implementation of which has been enshrined in both federal and provincial legislation,<sup>14</sup> states in Article 24:

*“Indigenous individuals have an equal right to the enjoyment of the highest attainable standard of physical and **mental health**. States shall take the necessary steps with a view to achieving progressively the full realization of this right.”*<sup>15</sup> (emphasis added)

Further, the *United Nations Convention on the Rights of Persons with Disabilities (UNCRPD)*, which includes those with neurodevelopmental conditions, states in Article 26:

*“States Parties shall take effective and appropriate measures ... to enable persons with disabilities to attain and maintain maximum independence, full physical, **mental**, social and vocational ability, and full inclusion and participation in all aspects of life. To that end, States Parties shall organize, strengthen and extend comprehensive habilitation and rehabilitation services and programmes, particularly in the areas of **health**, employment, education and **social services**, in such a way that these services and programmes:*

- a. *Begin at the earliest possible stage, and are based on the multidisciplinary assessment of individual needs and strengths ...”*<sup>16</sup> (emphasis added)

<sup>12</sup> United Nations General Assembly, *United Nations Convention on the Rights of the Child* (New York, N.Y.: UN Headquarters), 1989. Children are defined in the *UNCRC* as under the age of 18.

<sup>13</sup> World Health Organization, <https://www.who.int/about/governance/constitution>, accessed Dec. 20, 2022.

<sup>14</sup> The federal government’s *United Nations Declaration on the Rights of Indigenous Peoples Act* received Royal Assent on June 21, 2021, while B.C.’s *Declaration on the Rights of Indigenous Peoples Act* received Royal Assent on Nov. 28, 2019.

<sup>15</sup> United Nations General Assembly, *United Nations Declaration on the Rights of Indigenous Peoples* (New York, N.Y.: UN Headquarters), 2007.

<sup>16</sup> United Nations General Assembly, *United Nations Convention on the Rights of Persons with Disabilities (New York, N.Y.: UN Headquarters)*, 2006.

Having ratified these conventions, Canada has an obligation to ensure that its legislation, policies, programs and services affecting children comply with them. The responsibility to implement this obligation is shared by the provinces and territories since most areas of responsibility for matters affecting children, including health and social services, are under provincial and territorial jurisdiction.

*UNDRIP* and the *UNCRPD* are both referenced in the 2021 *Accessible British Columbia Act*, which establishes a legal framework to identify, remove and prevent barriers to the full and equal participation of people with disabilities. Amongst other matters, the Act requires government to develop a government-wide accessibility plan, which must be updated at least once every three years. The first iteration of that plan has been created but is silent with respect to mental health services for children and youth with neurodevelopmental conditions.<sup>17</sup> As will be made clear in this report, the Representative believes there is a compelling need and opportunity for government to incorporate improvements to mental health services to children and youth with neurodevelopmental conditions into the next iteration of that plan.

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<sup>17</sup> SBC 2021 (CHAPTER 19). *UNDRIP* is referenced in s.19 and the *UNCRPD* in s.18 to inform the establishment of standards. *Accessibility B.C.: B.C.'s Accessibility Plan 2022/23 to 2024/25* can be found at: <https://www2.gov.bc.ca/assets/gov/government/about-the-bc-government/accessible-bc/accessiblebc-plan.pdf>.

## The CHPC Report

As with the first report in this series about the mental health needs of children in care,<sup>18</sup> a crucial finding of the CHPC review is the very high prevalence of mental health disorders amongst children and youth with neurodevelopmental conditions, specifically those with ASD, FASD and ID. The CHPC's meta-analysis included the most rigorous Western-based epidemiological studies available respecting those three sub-populations which reported on five of the most common mental disorders, specifically: anxiety, major depressive disorder, attention-deficit/hyperactivity disorder (ADHD), oppositional defiant disorder (ODD) and conduct disorder.

**Anxiety disorders** - differ from normal feelings of nervousness or anxiousness and involve excessive fear or anxiety. In general, for a person to be diagnosed with an anxiety disorder, the fear or anxiety must be out of proportion to the situation or age-inappropriate and hinder ability to function normally.

There are several types of anxiety disorders, including generalized anxiety disorder, panic disorder, specific phobias, agoraphobia, social anxiety disorder and separation anxiety disorder.

**Major depressive disorder** - is a common and serious medical illness that negatively affects how one feels, thinks and acts. Depression causes feelings of sadness and/or a loss of interest in activities once enjoyed. It can lead to a variety of emotional and physical problems and can decrease ability to function at school and at home.

**Attention-deficit/hyperactivity disorder (ADHD)** - is one of the most common mental disorders affecting children. Symptoms of ADHD include inattention (not being able to keep focus), hyperactivity (excess movement that is not fitting to the setting) and impulsivity (hasty acts that occur in the moment without thought).

**Oppositional defiant disorder (ODD)** - a pattern of angry/irritable mood, argumentative/defiant behaviour, or vindictiveness lasting at least six months as evidenced by at least four symptoms of a list of types of oppositional behaviours exhibited during interaction with at least one individual who is not a sibling.

**Conduct disorder** - a repetitive and persistent pattern of behaviour in which the basic rights of others or major age-appropriate societal norms or rules are violated, as manifested by the presence of at least three of 15 specified criteria in the past 12 months, with at least one criterion present in the past six months.<sup>19</sup>

Looking at these five common diagnoses, the findings were:

- the prevalence of **anxiety disorders** is nearly eight times higher amongst children and youth with ASD than in the general child population (39.6 per cent versus 5.4 per cent); there was no appreciable difference in prevalence rates with ID (5.4 per cent versus 5.2 per cent) and no available data for FASD.
- the prevalence of **major depressive disorder** is more than eight times higher amongst children and youth with ASD than in the general child population (10.6 per cent versus 1.3 per cent); about 28 times higher for FASD (36 per cent versus 1.3 per cent) and about double for ID (2.5 per cent versus 1.3 per cent).

<sup>18</sup> See note 9.

<sup>19</sup> See note 7.

- the prevalence of **ADHD** amongst children and youth with ASD is more than nine times higher than in the general child population (34.8 per cent versus 3.7 per cent), more than 14 times higher for FASD (52.9 per cent versus 3.7 per cent) and more than double for ID (9.5 per cent versus 3.7 per cent).
- the prevalence rates of **ODD** are very similar across all three neurodevelopmental conditions and are almost four times higher than in the general child population for each of ASD, FASD and ID (12.6, 12.9 and 12.4 per cent, respectively, versus 3.3 per cent, with the rate for children with ASD also including conduct disorder).
- the prevalence of **conduct disorder** amongst children and youth with FASD is more than five times higher than in the general child population (7.0 per cent versus 1.3 per cent) and nearly four times higher for ID (5.1 per cent versus 1.3 per cent). See above regarding ASD and conduct disorder.

These findings are drawn from an analysis of epidemiological studies in high-income jurisdictions, which include some Canadian data. There is no reason to believe that the prevalence rates amongst children and youth with neurodevelopmental conditions in B.C. are any less than what is reported in the CHPC review. There may also be no reason to believe that in normal (non-pandemic) circumstances, the prevalence rates are any greater in B.C. than those reported in the CHPC findings, with two caveats. First, disaggregated data is not available with respect to First Nations, Métis, Inuit and Urban Indigenous children and youth with neurodevelopmental conditions. Given the adverse and intergenerational impacts of the traumas of colonization, together with the impacts of adverse socio-economic conditions<sup>20</sup> for far too many, prevalence rates may be higher amongst Indigenous children and youth with neurodevelopmental conditions.

A second caveat is that prevalence rates may have been significantly aggravated by the pandemic. This concern was highlighted in two research reports commissioned by the Representative and again carried out by the CHPC, which reviewed the relevant research to assess how the pandemic and its associated challenges may affect the mental health of B.C. children, including those who may be disproportionately harmed. The first report found dramatic and enduring increases in rates of anxiety, post-traumatic stress, depression and behavioural challenges during and following pandemics and other natural disasters in other jurisdictions. In referencing vulnerable groups that may be disproportionately impacted, the authors commented:

*“In addition, children with neuro-diverse developmental conditions may have greater mental health needs during the pandemic. For example, for children with autism spectrum disorder, the demands of quarantine, coupled with reductions in crucial services, may result in added distress for children and stress for parents.”<sup>21</sup>*

The second CHPC report, specific to the mental health impacts of COVID-19 on children, identified eight rigorous international studies, seven of which found that children’s mental health suffered during the pandemic, including three that found significantly more children likely met criteria for a mental

<sup>20</sup> For example, First Call’s *2022 BC Poverty Report Card* found that the child poverty rate on 59 B.C. First Nations reserves (where data was available) was 29.2 per cent, more than twice as high as the overall child poverty rate. <https://firstcallbc.org/bc-child-poverty-report-card/>.

<sup>21</sup> Children’s Health Policy Centre, *COVID-19 and the Impact on Children’s Mental Health* (Vancouver, B.C.: Simon Fraser University), 2020, p.14.

disorder, experienced clinically significant anxiety and experienced serious emotional difficulties. These increases were substantial, ranging from 48.1 to 94.2 per cent.<sup>22</sup>

As with prevalence rates amongst children in care, we should have – and indeed need to have – B.C.-specific data to appropriately inform service planning so we can more effectively meet the mental health needs of all children and youth with neurodevelopmental conditions in this province, including disaggregated data respecting First Nations, Métis, Inuit and Urban Indigenous children and youth with neurodevelopmental conditions. The Representative believes that it is vitally important for MMHA, which is responsible for setting strategic direction in B.C. to improve the mental well-being and reduce substance use-related harms for all British Columbians, to commission comprehensive research that identifies the prevalence of the range of mental health disorders amongst children and youth with neurodevelopmental conditions. That data can then be used to inform the development and implementation of appropriate services to respond to identified needs, linking those identified needs to service planning for the “reset” of the implementation of the CYSN Framework (or FCCs) and development of a system of services, including mental health services, that is to be co-created with Indigenous communities.

Regardless of future studies, what is eminently clear is that, like children in care, children and youth with neurodevelopmental conditions are vastly more likely to experience mental health challenges than the general child and youth population. In effect, children and youth with neurodevelopmental conditions who are already vulnerable due to their condition are far more likely to experience compounding vulnerabilities due to their mental health challenges. As the Representative noted in *A Parent’s Responsibility*, the experience of the pandemic has served to remind us of the need to direct resources to the most vulnerable as a first priority – in that case to the elderly, people in congregate care settings and immunocompromised individuals. Since children and youth with neurodevelopmental conditions are a sub-population that is known to be especially vulnerable to mental health challenges, one would expect that there would similarly be a prioritization of resources to address those needs, especially in circumstances where government has launched major social policy initiatives to address both the inadequacies of the mental health services system and to reform services to children and youth with support needs. That, unfortunately, has not been the case.

The second key component of the CHPC report is the identification of mental health interventions that, according to rigorous Western scientific standards, have been proven to be effective.<sup>23</sup> It is heartening to learn, for example, that specific types of adapted cognitive-behavioural therapy (CBT) are highly successful for children and youth with ASD, that certain types of parent training programs successfully reduced behaviour challenges for children with FASD and ID, and that there is emerging evidence of the effectiveness of social skills training for children with FASD. Unfortunately, the specific, proven

<sup>22</sup> Children’s Health Policy Centre, *COVID-19 and Children’s Mental Health: Implications for Pandemic Recovery* (Vancouver, B.C.: Simon Fraser University), 2023 (in press).

<sup>23</sup> It is worth repeating here that, while CHPC applies a rigorous approach to determining effectiveness of interventions, the Representative is aware that this may preclude other effective interventions that are either delivered in the context of non-Western scientific approaches or have not (yet) been evaluated/measured and reported on in Western scientific literature.

interventions in the CHPC report are not widely available in the province<sup>24</sup> and, in most cases, not available at all. They should be.

The Representative notes the lack of research into effective and culturally attuned mental health interventions with Indigenous children and youth, including those with neurodevelopmental conditions. This is a singular and glaring gap that must be addressed. It is critical that all interventions for First Nations, Métis, Inuit and Urban Indigenous young people are developed or co-created by Indigenous communities in ways that ensure the inclusion of Elders, Matriarchs, Knowledge Keepers and Healers as well as service providers. Moreover, these programs need to be delivered in ways that embrace traditional Indigenous knowledge and values, such as the *Culture is Healing* framework developed by Indigenous Child and Family Services Agency Directors.<sup>25</sup>

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<sup>24</sup> The Representative is aware that one identified program, Triple P Parenting, is available in some locations in the province. Moreover, CBT is widely employed by CYMH clinicians; however, program delivery adaptations are required for this unique population such as those identified in the CHPC report.

<sup>25</sup> See the Indigenous Child and Family Services Agencies (ICFSA) Directors *Our Children, Our Way* website, <https://ourchildrenourway.ca>. *Culture is Healing* is grounded in the *Aboriginal Policy and Practice Framework* (APPF, 2015) rooted in traditional values and beliefs and improving outcomes for Indigenous children, youth, families and communities through restorative policies and practices. *Culture is Healing* takes a holistic approach to well-being by integrating the four guiding principles drawn from the APPF and adopted by the ICFSA Directors Forum: culture-centred; inclusive and accountable; wellness-focused; and child-, youth-, family- and community-centred.



## Previous Reports and Recommendations

The CHPC report is not the first to identify the heightened mental health needs of children and youth with support needs, including those with neurodevelopmental conditions, though it is the first to do so by employing a rigorous scientific analysis of the research literature. RCY has had long-standing concerns about the adequacy of mental health services for children and youth generally as well as services for children and youth with support needs and has released a number of related reports, with recommendations.

The most salient of these in relation to mental health services include *Still Waiting: First-hand Experiences with Youth Mental Health Services in B.C.* (2013), which involved an extensive review of mental health services and consultations with youth, families, service providers and experts.<sup>26</sup> That report, which identified youth with developmental disabilities and co-occurring mental health problems as a particularly vulnerable sub-population requiring unique care, recommended, amongst other matters, the establishment of a minister responsible for youth mental health as well as adequate resources to develop and implement a full continuum of mental health services for youth ages 16 to 24.

There have also been five investigations into critical injuries and deaths where the inadequacies of mental health services were a core concern, including:

- A 2013 investigative report into critical injuries to a young person with complex needs including ID and co-occurring mental health problems which, amongst other matters, recommended MCFD establish a continuum of residential services for children and youth with complex needs and an internal clinical unit to provide consultation, training and clinical support to residential staff dealing with children and youth with complex needs.<sup>27</sup>
- A 2014 investigative report into the suicide of a 14-year-old First Nations girl with significant ID, which recommended immediate steps to provide for effective mental health services generally and, in particular, for Indigenous children and youth.<sup>28</sup>
- An investigative report in 2016 into the suicide of another First Nations youth which detailed the inadequacies of mental health services for Indigenous children and made recommendations for improvements.<sup>29</sup>
- *Missing Pieces: Joshua's Story* (2017), an investigative report which called upon MMHA to lead the planning and implementation of a full continuum of mental health services for children and youth.<sup>30</sup>

<sup>26</sup> Representative for Children and Youth, *Still Waiting: First-hand Experiences with Youth Mental Health Services in B.C.* (Victoria, B.C.: Representative for Children and Youth), 2013.

<sup>27</sup> Representative for Children and Youth, *Who Protected Him? How B.C.'s Child Protection System Failed One of Its Most Vulnerable Children* (Victoria, B.C.: Representative for Children and Youth), 2013.

<sup>28</sup> Representative for Children and Youth, *Lost in the Shadows: How a Lack of Help Meant a Loss of Hope for One First Nations Girl* (Victoria, B.C.: Representative for Children and Youth), 2014.

<sup>29</sup> Representative for Children and Youth, *A Tragedy in Waiting: How B.C.'s mental health system failed one First Nations youth* (Victoria, B.C.: Representative for Children and Youth), 2016.

<sup>30</sup> Representative for Children and Youth, *Missing Pieces: Joshua's Story* (Victoria, B.C.: Representative for Children and Youth), 2017.

- The investigation into the death of Alex Gervais – *Broken Promises: Alex’s Story* (2017) – which recommended that, amongst other matters, MCFD ensure that Aboriginal Child and Youth Mental Health (ACYMH) services be sufficiently resourced to be able to accommodate all Indigenous children and youth who require screening, assessment and/or outreach services in a timely manner.<sup>31</sup>

While all five investigations expressed serious concerns about the adequacy of mental health services for children and youth, it is notable that two also involved youth with neurodevelopmental conditions.<sup>32</sup>

The Representative’s concerns about the inadequacies of child and youth mental health were echoed in a special project review undertaken by the Select Standing Committee on Children and Youth in 2016, *Final Report, Child and Youth Mental Health in British Columbia: Concrete Actions for Systemic Change*.<sup>33</sup> That report identified significant weaknesses and gaps in the service system and made a number of wide-ranging recommendations for reform of – and investment in – the system of child and youth mental health services, including the appointment of a dedicated minister. Notably, that report recognized the particular vulnerabilities of children and youth with support needs and recommended that the provincial government:

*“Make children, youth and young adults with special needs a priority in child and youth mental health services, and integrate these needs in work on the redesign and strengthening of services.”*<sup>34</sup>

In addition to the two investigative reports involving youth with neurodevelopmental conditions who had concurrent and significant mental health problems, the Representative has completed three reports in recent years that have addressed the inadequacies of the systems of services to children and youth with support needs, including those with neurodevelopmental conditions.

*Alone and Afraid: Lessons learned from the ordeal of a child with special needs and his family* (2018) was an investigative report into the critical injuries of a 12-year-old non-verbal boy with ASD who suffered profound neglect.<sup>35</sup> A key recommendation was that MCFD carry out a comprehensive needs assessment to inform the development and implementation of a plan so that all eligible children with support needs and their families receive culturally respectful, appropriate and timely services and supports.

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<sup>31</sup> Representative for Children and Youth, *Broken Promises: Alex’s Story* (Victoria, B.C.: Representative for Children and Youth), 2017.

<sup>32</sup> Two additional recent RCY reports concerning mental health services related to more narrowly framed issues, i.e., the rights of youth detained in hospital under the *Mental Health Act* and non-suicidal self injury. See, *Detained: Rights of children and youth under the Mental Health Act* (2021) and *A Way to Cope: Exploring non-suicidal self-injury in B.C. youth* (2020).

<sup>33</sup> Select Standing Committee on Children and Youth, *Final Report, Child and Youth Mental Health in British Columbia: Concrete Actions for Systemic Change* (Victoria, B.C.: Legislative Assembly of British Columbia), 2016.

<sup>34</sup> *Child and Youth Mental Health in British Columbia*, Recommendation 23, p. 50.

<sup>35</sup> Representative for Children and Youth, *Alone and Afraid: Lessons learned from the ordeal of a child with special needs and his family* (Victoria, B.C.: Representative for Children and Youth), 2018.

*Left Out: Children and youth with special needs in the pandemic* (2020) detailed the immense challenges facing children and youth with support needs and their families during the pandemic.<sup>36</sup> The report called on government to address both the urgent and immediate needs of children and youth with support needs who have been neglected during the pandemic and to begin a system overhaul aimed at providing inclusive, equitable and needs-based services. Consultations for that report also highlighted increased mental health concerns during the pandemic observed by parents, caregivers and service providers. This issue was also highlighted in the previously mentioned research reports commissioned by the Representative and carried out by the CHPC, which reviewed the relevant research to assess how the pandemic and its associated challenges may affect the mental health of B.C.'s children, including those who may be disproportionately harmed, such as children and youth with support needs.<sup>37</sup>

The RCY report, *Excluded: Increasing Understanding, Support and Inclusion for Children with FASD and their Families* (2021), detailed how children and youth with FASD, and their families, do not receive necessary and appropriate supports to meet their unique needs.<sup>38</sup> These inequities and service gaps are apparent across the full range of services, including services to children and youth with support needs, educational services and mental health services. The report reiterated the call in the previous two reports for MCFD to fully fund and implement a CYSN service framework and plan, and also specifically recommended that MMHA lead a review and develop and implement a plan to provide effective and accessible mental health services for children and youth with support needs, including FASD.

The Select Standing Committee on Children and Youth conducted a special review of services to children and youth with neuro-diverse needs in 2019, which recommended a wide range of reforms to the services system.<sup>39</sup> That report was, however, silent in relation to mental health services, perhaps because, as noted above, the Committee had previously made a specific recommendation in this regard in a 2016 report.

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<sup>36</sup> Representative for Children and Youth, *Left Out: Children and youth with special needs in the pandemic* (Victoria, B.C.: Representative for Children and Youth), 2020.

<sup>37</sup> See notes 21 and 22.

<sup>38</sup> Representative for Children and Youth, *Excluded: Increasing Understanding, Support and Inclusion for Children with FASD and their Families* (Victoria, B.C.: Representative for Children and Youth), 2021.

<sup>39</sup> Select Standing Committee on Children and Youth, *Children and Youth With Neuro-Diverse Needs* (Victoria, B.C.: Legislative Assembly of B.C.), 2019.

An article in the *BC Medical Journal* in 2019 – co-authored with Dr. Robin Friedlander, a leading clinical expert in the province – reported on a review and analysis of services in B.C. for children and youth with neurodevelopmental conditions who have co-occurring mental health disorders. The authors described four clinical vignettes to illustrate the challenges in obtaining appropriate services faced by these children, youth and their families.<sup>40</sup> The authors observed:

*“As the clinical vignettes illustrate, children and families trying to access services for co-occurring neurodevelopmental and psychiatric disorders face a number of barriers caused by system fragmentation, bureaucratic processes, lack of respite, out-of-home service obstacles, and limited specialized training for care providers.”*

They also noted:

*“If children with neurodevelopmental disorders are assessed as “too severe” or “low functioning,” they are often denied mental health services, regardless of mental health concerns or diagnosed psychiatric comorbidities.”*<sup>41</sup>

The article made a number of important recommendations for system improvements, including that MCFD’s CYMH:

- provide services to children with dual diagnosis<sup>42</sup>
- assign designated clinicians on teams for dual-diagnosis cases, similar to concurrent disorder clinicians on mental health teams
- provide more staff training in specialized therapy for dual diagnosis.<sup>43</sup>

Finally, in response to government’s now-paused plan to implement FCCs throughout the province and to cease individualized funding, Autism BC reported on the responses of 1,563 parents and caregivers of children and youth with autism to a number of survey questions.<sup>44</sup> In response to one part of the survey, parents and caregivers reported 60 per cent of their children experienced anxiety or an anxiety disorder, 17 per cent depression, 53 per cent ADHD and eight per cent ODD. Accordingly, the report recommended that government:

*“... integrate wraparound mental health and flexible respite services into all CYSN programs as part of their core services approach and delivery.”*<sup>45</sup>

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<sup>40</sup> Erika Ono, Robin Friedlander and Tamara Smith, “Falling through the cracks: How service gaps leave children with neurodevelopmental disorders and mental health difficulties without the care they need,” *British Columbia Medical Journal*, vol. 61, No. 3, (April 2019); p. 114-124.

<sup>41</sup> “Falling through the cracks,” p.120.

<sup>42</sup> Dual diagnosis refers to individuals who have ID and co-occurring mental health disorders.

<sup>43</sup> “Falling through the cracks,” p.122.

<sup>44</sup> Autism BC, *Parent and Caregiver Perspectives on the Family Connection Centres: Autism BC Survey Results*, November 2022.

<sup>45</sup> *Parent and Caregiver Perspectives*, p.74.

## Government's Responses

Government has taken a number of steps to address the inadequacies of mental health services for children and youth documented above. In 2017, MMHA was created. In June 2019, this ministry released a 10-year plan, *A Pathway to Hope: A roadmap for making mental health and addictions care better for people in British Columbia*.<sup>46</sup> This document has a major focus on child and youth mental health services and sets out priority actions, which involve the incremental implementation of new services and supports for children and youth, such as the expansion of Foundry Centres to new locations (23 total by 2025-26) for youth 12- to 24-years-old, the establishment of new multi-disciplinary integrated child and youth teams in 20 of the province's 60 school districts by 2024 and new step-up/step-down services.<sup>47</sup>

As noted in the Representative's earlier report in this series, *A Parent's Responsibility*, A Pathway to Hope is, apart from Indigenous peoples, silent with respect to other distinct sub-populations of children and youth who have heightened mental health vulnerabilities, such as children and youth with neurodevelopmental conditions, children in care and gender diverse youth. One would expect that a comprehensive plan for systemic reform of mental health services for children and youth would detail measures to address the distinct needs of these especially vulnerable groups, but *A Pathway to Hope* does not. That is perhaps a reflection of the reality that the document was not intended to be a comprehensive plan. *A Pathway to Hope's* intentions in relation to children and youth are currently limited to expanding programmatic solutions such as the Foundry, early years enhancements, school-based integrated teams, and community-based step-up/step-down outreach services. Unfortunately, the scope of these services pales in comparison to the need, with only 15 Foundry locations operational, and early years enhancements, school-based integrated teams and community step-up/step-down outreach services only operational in five communities as of the time of this report. Further, *A Pathway to Hope's* promised bed-based step-up/step-down services for children and youth who require a greater level of care and support than what is available in the community is still under development, with proposed services limited to two locations. A comprehensive plan for child and youth mental health should provide for universal expansion of core programs, including better addressing the understaffing and wait lists in MCFD's CYMH and Indigenous CYMH (ICYMH) services that persist today, while also addressing the distinct needs of vulnerable sub-populations such as children and youth with neurodevelopmental conditions

<sup>46</sup> British Columbia Ministry of Mental Health and Addictions, *A Pathway to Hope: A roadmap for making mental health and addictions care better for people in British Columbia* (Victoria, B.C.: Ministry of Mental Health and Addictions), 2019.

<sup>47</sup> Foundry is a network of integrated health and wellness services for young people ages 12- to 24-years-old. The integrated services make it possible for young people to access five core services in one convenient location: mental health care, substance use services, physical and sexual health care, youth and family peer supports, and social services. Foundry centres are currently operational in 15 communities, <https://foundrybc.ca/>. Integrated child and youth teams are currently operational in five school districts with another seven school districts planned for 2023, <https://www2.gov.bc.ca/gov/content/governments/about-the-bc-government/mental-health-and-addictions-strategy/integrated-child-youth-teams>. Bed-based step-up/step-down services are intermediate services that provide short-term residential support and individualized care for people following discharge from a mental health facility/hospital to better support their transition to community. They are also for those in the community who require a greater level of care and support than what is available in the community in order to avoid hospitalization. MCFD has, however, established some outreach non-residential step-up/step-down services in some locations and is in the course of repurposing two existing complex care residential programs into step-up/step-down residential services.

and those in care. A comprehensive plan would also embrace a “whole child” approach<sup>48</sup> and identify opportunities to support mental health and well-being – especially for more vulnerable populations – across ministries and services lines. *A Pathway to Hope* contemplates this by acknowledging the role of the health care system in the Foundry Centres, and the role of the education system in the integrated child and youth teams. A comprehensive child and youth plan could and should build on this foundation.

In recent years, MCFD has developed service frameworks which are intended to describe what services and supports need to be available for the children, youth, families and communities the ministry serves, how they can be accessed and the outcomes these services and supports are intended to achieve. Following release of *A Pathway to Hope*, MCFD released the *Child and Youth Mental Health Service Framework* in October 2019.<sup>49</sup> The CYMH Framework does address mental health services for children and youth with neurodevelopmental conditions, saying that CYMH:

*“Provides assessment and treatment for mental health disorders when there is a co-occurring developmental disability (e.g., mild intellectual disability, autism spectrum disorder and/or fetal alcohol spectrum disorder). This is done in partnership with regional and provincial health authorities and ministries.”*

In October 2021, MCFD released its *Children and Youth with Support Needs Framework and Service Description*, which sets out the parameters of the proposed (now pilot) FCCs and suggests referral links should be part of mental health services, but stops short of making them a core component of services:

*“When needed, services for children and youth with support needs can offer connections between the child or youth and their family and relevant services (e.g., facilitated connections to MCFD’s Child and Youth Mental Health (CYMH) services).”*

The Request for Proposals for the FCC sites also provided that the contractor must make space available for mental health professionals to work but did not make provision of mental health services a fundamental feature of the design of FCCs as they were not provided for in the contract and presumably could only be delivered by MCFD’s CYMH services or other services such as integrated child and youth teams, and in accordance with the capacity of that program to deliver the required services.<sup>50</sup>

MMHA’s *A Pathway to Hope* is a major social policy initiative which, to government’s credit, has attracted substantive new funding investments.<sup>51</sup> Yet, despite clear evidence of inadequate services and despite previous recommendations, the mental health needs of children and youth with neurodevelopmental conditions have been ignored.

<sup>48</sup> See text box on page 4.

<sup>49</sup> Ministry of Children and Family Development, *CYMH Service Framework*, October 2019.

<sup>50</sup> See, BC Bid, Ministry of Children and Family Development, Request for Proposal, *Child and Family Support Services*, BPM005229.

<sup>51</sup> The recently released *Budget and Fiscal Plan 2023/24 to 2025/25* allocates an additional \$867 million over three years for additional mental health and addictions services, however, this new funding appears to be overwhelmingly dedicated to services to adults. Where services to children and youth are referenced, it is in the context of addictions services, not mental health services; see, <https://www.bcbudget.gov.bc.ca/2023/default.htm>.

The (now paused) CYSN Framework with proposed FCCs was also a significant government social policy initiative. Yet, although mental health services were referenced in the CYSN Framework and FCC request for proposals, that initiative also did not attract new investment for these needed services. Indeed, the CYSN Framework announced in 2021 did not attract new investments into services for children and youth with support needs generally, despite the intention to expand services to a broader population, a failing that heightened the fears of families of children with ASD that their access to services would be diminished in order to expand the scope of and access to services for other sub-populations and which, as a result, led to mistrust by many families of government's intentions.

Indeed, these two major social policy initiatives appear to be disconnected and working in isolation from one another. To illustrate, new integrated child and youth teams have been established in five school districts under the *A Pathway to Hope* initiative, while pilot FCC sites are being established in four communities. One would expect that these two initiatives would be coordinated to enable linkages and complementary services between the two, yet only one FCC site has an established ICY team<sup>52</sup> and there are no apparent linkages between them that are clearly identified in planning documents.

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<sup>52</sup> The Coast Mountain School District has an established ICY team.

## RCY's Recommendations Tracking

RCY has established a process of following up on recommendations in its reports, which involves ministries and public bodies submitting action plans within six months of each report release and reporting on implementation thereafter, which is tracked, assessed and publicly reported on the RCY website.<sup>53</sup> The recommendations monitoring process reveals a great deal about actual – rather than just promised – progress and is therefore a vital tracking tool used by the Representative's Office. The most salient of the Representative's previous recommendations in respect of mental health services to children and youth with neurodevelopmental conditions was made in the *Excluded* report on FASD, which in full stated:

*“That the Ministry of Mental Health and Addictions (MMHA), in collaboration with MCFD, ICFSAs and the Ministry of Health (HLTH), lead a review, and develop and implement a plan, to provide effective and accessible mental health services for children and youth with special needs, including FASD. This should include a review of evidence-based, culturally attuned and promising practice models of therapy, intervention and care for children and youth with special needs including FASD, who have mental health impacts, as well as an assessment of current resourcing and resource gaps. The findings of this review and planning should be prioritized and built into MMHA's A Pathway to Hope for implementation.*

*MMHA to complete the review and plan by March 31, 2022, with MCFD and HLTH beginning the implementation of new service approaches and enhanced services by Oct. 1, 2023, and completing implementation by March 31, 2024.”*<sup>54</sup>

Although the *Excluded* report was specific to FASD, the above-noted recommendation called for effective and accessible mental health services for all children and youth with support needs to avoid the anomalous outcome of services being developed for children and youth with FASD but excluding other neurodevelopmental conditions such as ASD and ID.

In assessing government's response after the first year, the Representative stated:

*“No progress.*

*The Representative has assessed MMHA's Year 1 progress report and found that it has begun pre-planning the review to identify effective and accessible mental health services for children and youth with special needs, including FASD. At the time of MMHA's Year 1 Report, the review had not begun, and is now overdue as the Representative called for the work to be completed by March 31, 2022. The Representative has not yet approved the Action Plan and is awaiting more information from MMHA on the implementation and resourcing of necessary system improvements.”*<sup>55</sup>

The lack of action to improve mental health services to children and youth, along with government's apparent intention to address the mental health needs of children and youth with support needs within current resources,<sup>56</sup> raises questions about the current state of those services. This matter is discussed below.

<sup>53</sup> Representative for Children and Youth, “Developing and tracking recommendations,” November 2022, <https://rcybc.ca/reports-and-publications/recommendations/>.

<sup>54</sup> Representative for Children and Youth, *Excluded*, p. 101.

<sup>55</sup> <https://rcybc.ca/reports-and-publications/recommendations/>.

<sup>56</sup> There is no provision for new funding for mental health services for CYSN children in either *A Pathway to Hope* or the implementation of the CYSN Framework.



## Current Services

Publicly funded mental health services to children and youth with neurodevelopmental conditions are delivered by four primary means:

- through CYMH services directly delivered or contracted by MCFD
- specialized Developmental Disabilities Mental Health Services (DDMHS), which are partially funded by MCFD and delivered by health authorities
- tertiary care hospital services operated by health authorities
- “complex care” intervention programs delivered or funded by MCFD that are largely targeted to children and youth with support needs but limited to children in care.<sup>57</sup>

Comprehensive and accurate data – even the most basic data, such as numbers served – about mental health services to children and youth with neurodevelopmental conditions is not available due to fragmentation of service delivery and because when data is captured – if it is captured at all – it is not detailed enough to be useful.<sup>58</sup> For example, MCFD’s CYMH services provide community-based mental health services to children and youth, including those with neurodevelopmental conditions, through 88 teams across the province.<sup>59</sup> However, data about children and youth with neurodevelopmental conditions who are served is not readily accessible at all for some areas of the province – notably Vancouver/Richmond – because services are contracted for those areas.

In the remainder of the province where CYMH directly delivers services, data respecting the number of children with neurodevelopmental conditions (of any type) is only accessible for clients who have been discharged from the “active phase” of CYMH services, however, it may be collected as part of the initial clinical assessment.<sup>60</sup> Moreover, data is only available respecting ASD and ID for this limited group of clients, but not specifically for FASD. The data from discharged clients, which represent only 25 per cent of the clients served, indicate that, in the 2021/22 fiscal year, 3,547 children and youth were discharged from the active phase of mental health services; 204 children and youth had an ASD diagnosis and

<sup>57</sup> Additional services may be indirectly publicly funded. Families who access Autism Individualized Funding are able to decide how to spend their allotted funding to best support their child/youth and family; see, <https://www2.gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/support-needs/autism-spectrum-disorder/autism-funding>. Children under six-years-old can receive a maximum of \$22,000 per year, while children over six receive a maximum of \$6,000 per year. The funds allow families to purchase services and interventions that promote their child’s communication, social-emotional, academic and functional life skills development and which can, for example, include private psychological or psychiatric services. Data is not available regarding the extent to which this funding is used for private mental health services.

<sup>58</sup> Unless otherwise specified, all information and data in this section was provided by MCFD, health authorities and Community Living BC by way of a legally binding request for information made pursuant to s.10 of the *Representative for Children and Youth Act*.

<sup>59</sup> MCFD’s 2020 *CYMH Service Inventory* indicates there are 72 directly staffed MCFD teams, 15 teams contracted through the Vancouver Coastal Health Authority, and one contracted team in Prince George.

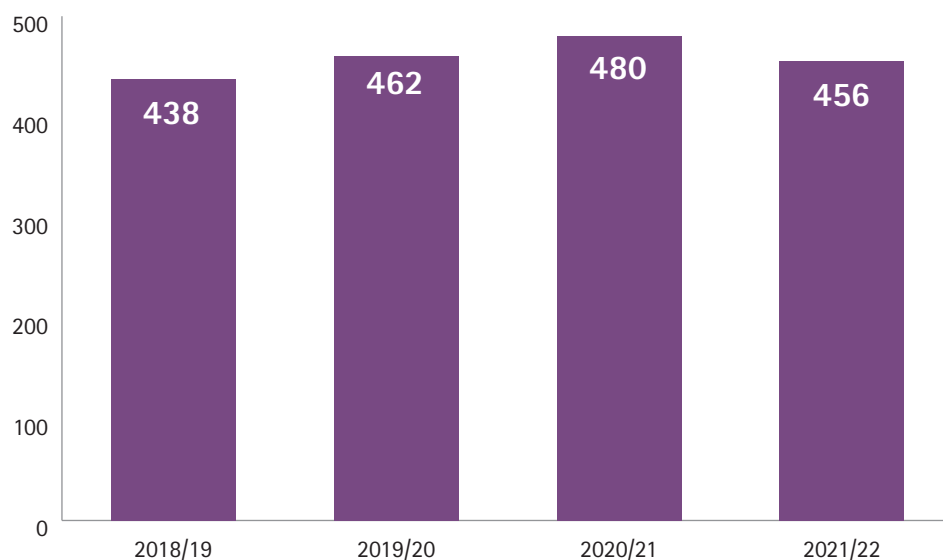
<sup>60</sup> The CYMH information system captures four phases of services: referral, initial services, active and follow-up. Clients do not necessarily complete all phases. For example, referred clients may seek services elsewhere or not engage in initial services while those who engage in initial services may not proceed further or complete services. Diagnostic worksheets, which use the Diagnostic and Statistical Manual of Mental Disorders (DSM-5), are not completed for the first two phases but are entered in the system for clients in the active phase and are a requirement for file closure. The Representative will be examining the flow and attrition of cases through these phases in the future.

88 had an ID diagnosis, which represents about six per cent and two per cent, respectively, of the active cases discharged that year.

MCFD’s 2020 *CYMH Service Inventory* indicates that none of the CYMH teams in the province specialize in services to children and youth with neurodevelopmental conditions, nor are there dedicated specialists for this population;<sup>61</sup> rather, some youth may be referred to contracted DDMH services, which, as will be discussed later, are limited in eligibility. Although MCFD has not to date provided specialized training for CYMH mental health clinical staff in services to children and youth with neurodevelopmental conditions, it is heartening to see that the ministry is commencing training of mental health clinicians in 2023 on neurodiversity and anxiety with a focus on adapting the core principles of CBT, promoting social skills development and addressing caregiver supports.<sup>62</sup> It is less heartening to see, however, that this one-time training will be available to less than one-third of mental health clinicians in the province.<sup>63</sup>

Generally speaking, and despite the *A Pathway to Hope* initiative that was announced in 2019, the service and resource challenges first outlined in the 2013 RCY report *Still Waiting* continue today. As Figure 1 indicates, MCFD’s frontline CYMH staffing level only modestly improved – by four per cent – between fiscal years 2018/19 and 2021/22, although it is noted that staffing actually declined (by five per cent) from the peak in the previous year, which may be related to the pandemic and the recruitment and retention challenges currently being faced by many service areas.<sup>64</sup>

Figure 1 – Monthly Average Active Frontline CYMH Employee Counts



<sup>61</sup> Ministry of Children and Family Development, *Child and Youth Mental Health Service Inventory*, 2020.

<sup>62</sup> BC Bid, *Training in Neurodiversity and Anxiety*, XCN2022-075RFP.

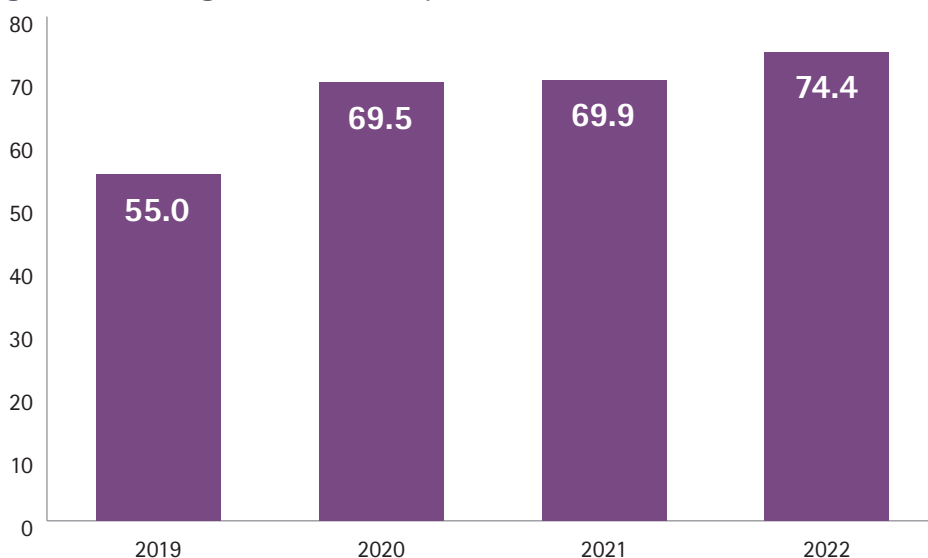
<sup>63</sup> The one-time training is to be offered to up to 150 clinicians. MCFD reports a clinician and team leader employee count of 519 in the 2021/22 fiscal year but this excludes clinicians in Vancouver/Richmond and Prince George because services are contracted out in those locations.

<sup>64</sup> Employee counts include full- and part-time staff. An alternative measure of FTE “burn” (or utilization) produces very similar results. 2019 is selected as a base year because that is when *A Pathway to Hope* was announced.

Wait lists for CYMH services persist. MCFD reports there were 6,812 children and youth wait-listed for directly delivered CYMH services in the 2021/22 fiscal year, excluding Vancouver/Richmond and Prince George. The ministry does not know how many of those wait-listed were children and youth with neurodevelopmental conditions.

As Figure 2 indicates, average waiting times have progressively and substantively increased (by 35 per cent) over the past four years, from an average of 55 days in 2019 to 74.4 days in 2022. Average wait times can vary considerably by area, for example, from a low of 38 days in MCFD's Northwest service delivery area to a high of 202 days in the North Central area in 2022. The average wait time for Indigenous children and youth was slightly less than for non-Indigenous children and youth (70 versus 77 days) in 2022.

Figure 2 – Average Number of Days To First CYMH Service<sup>65</sup>



Moreover, MCFD's 2020 *CYMH Service Inventory*, which collated information provided by all 88 teams, reported that workload pressures (77 per cent),<sup>66</sup> staffing (67 per cent) and training (76 per cent) were key challenges to providing therapy and intervention services. With such resource and capacity limitations, it is understandable that services to children and youth with neurodevelopmental conditions would also be very limited.

DDMHS are specialized community-based mental health services that are delivered by health authorities by way of contract<sup>67</sup> with MCFD for developmentally disabled (or ID) youth who are either 12- or 14-years-old or older (depending on the region) experiencing serious co-occurring mental health challenges. These eligibility criteria therefore exclude all younger children with neurodevelopmental conditions and the substantial majority of youth with ASD and FASD who do not meet the threshold of ID.<sup>68</sup> Health authority data was only available for Fraser and Vancouver Coastal DDMHS which

<sup>65</sup> To ensure comparability of time periods, the average number of days from April 1 to Dec. 31 for each year is presented.

<sup>66</sup> See note 61.

<sup>67</sup> MCFD reports a contract total of \$891,871 in fiscal year 2021/22 for DDMHS services.

<sup>68</sup> See textbox on page 5.

indicated that, in fiscal year 2021/22, there was a total of 36 new intakes and an average of 114 youth served per month who received an average of 2.3 hours of individual services.

MCFD's 2020 *CYMH Service Inventory* highlighted a number of challenges in accessing DDMH services. It noted that the programs were small, had restrictive referral criteria, were difficult in some areas to access due to their expansive geographies, provided only limited services, and there was a lack of specialized training for CYMH teams that were trying to provide a "stop-gap" measure where other DDMH services were not available.

In addition to DDMHS contracts, there are some additional CYMH-related contracted agencies that provide services to children and youth with neurodevelopmental conditions and co-occurring mental health challenges, however, MCFD reported that it is not possible to readily estimate the number or dollar value of these contracted services.

Hospital tertiary care services are provided through health authorities, such as at BC Children's Hospital and Sunny Hill Health Centre, but service utilization to children and youth with neurodevelopmental conditions is not specifically recorded. There are no specialized inpatient psychiatric services for children and youth with neurodevelopmental conditions in the province.<sup>69</sup> Ono, Friedlander and Smith report that many children with neurodevelopmental disorders who are referred to child or adolescent psychiatry units are declined service.<sup>70</sup>

The Provincial Health Services Authority operates a small inpatient psychiatric stabilization and assessment unit – the Provincial Assessment Centre (PAC) – for CLBC-eligible developmentally disabled individuals which may accept referrals of youth who are 14 or older.<sup>71</sup> This specialized program is principally for adults and is only able to provide very limited services to youth.<sup>72</sup> Only two of the 42 admissions to the program in the three-year period between fiscal years 2019/20 and 2021/22 were youth at the time of admission. There were eight referrals of youth in the 2021/22 fiscal year, all of whom were wait-listed.

In 2014, MCFD implemented the Children and Youth with Complex Care Needs (CYCCN) Model of Care, a specialized clinical service for children in care that has four components: the six-bed Complex Care Unit at the Maples Adolescent Treatment Centre; contracted community care beds in Prince George and Vernon (five beds each); a provincial outreach team; and the community-based Complex Care Intervention (CCI) services. The program has a narrow scope as it is principally oriented to children with developmental disabilities and co-occurring mental health concerns and is limited to children in care. As the vast majority of children and youth with neurodevelopmental conditions are not in care, this specialized clinical service is not available to them.

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<sup>69</sup> See note 40.

<sup>70</sup> See note 40.

<sup>71</sup> Responsibility for this program was transferred from CLBC to PHSA on Feb. 28, 2023; see [https://www.bclaws.gov.bc.ca/civix/document/id/oic/oic\\_cur/0128\\_2023](https://www.bclaws.gov.bc.ca/civix/document/id/oic/oic_cur/0128_2023).

<sup>72</sup> PAC reports that referred youth typically have extensive management needs, require extra staffing and a separate area.

The CYCCN has been significantly under-utilized in the past. For example, in the 2021/22 fiscal year, there were 12 admissions to the Complex Care Unit, six admissions to the community care beds and 32 admissions to the outreach program. The number of admissions does not equate to the number of children and youth served as the same individual could be admitted to all three programs or admitted to the same program several times in the course of the year. Through the month of March 2022, the average number of youth in the six-bed Complex Care Unit was 2.6, while the average was 1.1 in the (combined) 10 community care beds. Services provided through the CYCCN Model of Care are currently being reconfigured.<sup>73</sup>

The piecemeal nature of the data described above precludes a fulsome assessment of how well current mental health services are meeting the needs of children and youth with neurodevelopmental conditions. Nonetheless, services, too, are piecemeal and serve relatively small numbers of children and youth. This should be contextualized against the potential need for services; for example, MCFD reports that in March 2022, there were 24,127 children and youth in the province in receipt of individualized autism funding payments, a significant portion of whom would, according to the CHPC report, experience mental health challenges. Further, the prevalence of FASD amongst children and youth is estimated to be double that of ASD yet, as detailed in RCY's *Excluded* report, the vast majority of these vulnerable children and youth receive little or no services, including mental health services, even though they too have very high rates of prevalence of mental health challenges. Similarly, the prevalence rate of ID is three times the rate of ASD.<sup>74</sup>

A recurring concern of the Representative across many service areas is inadequate data gathering by ministries and public bodies. In this regard, RCY's 2021 *Excluded* report recommended the development of a cross-ministry plan to routinely collect high-quality demographic and service data that allows for disaggregation, providing an essential foundation for more effective policy development, program provision and service monitoring for children and youth with neurodevelopmental conditions and their families, including those with FASD.<sup>75</sup> As reported on the RCY website in June 2022, the Representative assessed that no progress had yet been made in implementing this recommendation.<sup>76</sup> The inadequacies of the data described above underscore the need to move forward with a clear plan and implementation of that plan.

<sup>73</sup> An operational review of the provincial CYCCN services in 2019 found that, over the course of five-and-a-half years, the program had served only 66 children through outreach services, 29 children in contracted community care beds and 25 children at the Complex Care Unit, with extraordinarily high per diem rates in the residential components due to very low occupancy rates (*CYCCN Residential Services Utilization Review Summary Report* draft report, MCFD, Sept. 23, 2019).

<sup>74</sup> See note 6.

<sup>75</sup> Development of the plan is being led by the Ministry of Citizens' Services.

<sup>76</sup> [https://rcybc.ca/wp-content/uploads/2022/11/Excluded-RCY-Year-1-Annual-Assessment\\_FINAL\\_2-Nov-2022.pdf](https://rcybc.ca/wp-content/uploads/2022/11/Excluded-RCY-Year-1-Annual-Assessment_FINAL_2-Nov-2022.pdf). Recommendation 9.

## The Representative's Case Information

The Representative routinely learns of services being provided to children and youth with neurodevelopmental conditions through reports of critical injuries and deaths and through individual advocacy services RCY provides to children, youth and their families. The Representative also receives information from provincial and local community service organizations about the state of services and supports for these children and youth and their families where there are co-occurring mental health concerns. These stories reveal a broad range of significant concerns about the provision of mental health services to these children and youth, including: lack of training or no training at all of staff to deal with the complexities of co-occurring disorders; inadequate or no screening and assessment; wait lists for service or no service at all; abrupt and early curtailment of services; lack of culturally attuned and relevant mental health care for First Nations, Métis, Inuit and Urban Indigenous children and youth; inadequate intensity of service; lack of coordination of services and collaborative planning; and inadequate discharge planning from hospital or tertiary care, including largely non-existent bed-based “step-up/step-down” services.

The *Representative for Children and Youth Act (RCY Act)* requires public bodies responsible for the provision of a service to report critical injuries and deaths to the Representative, but this requirement is limited to reviewable services which include child welfare, youth justice, mental health and addictions services for children and youth.<sup>77</sup> Services provided by MCFD and health authorities to children and youth with support needs – including those with neurodevelopmental conditions – are not reviewable services. RCY does regularly receive reports of children and youth with neurodevelopmental conditions who are critically injured or die but only about those who are concurrently involved in a reviewable service such as child welfare services. Since these children and youth represent only a small proportion of children and youth with neurodevelopmental conditions in receipt of publicly funded services,<sup>78</sup> RCY data respecting critical injuries and deaths is not representative of the whole population of children and youth with neurodevelopmental conditions, and therefore will not be presented. Nonetheless, the critical injury reports the Representative does receive about children and youth with neurodevelopmental conditions often indicate those children experience concurrent mental health challenges with accompanying difficulties in accessing appropriate services. After the Representative receives a report of a critical injury or death, a case review is conducted. The case vignettes described below are examples of the typical and current challenges in accessing appropriate mental health services by critically injured youth.<sup>79</sup>

<sup>77</sup> See s.1 and s.11 of the *RCY Act*.

<sup>78</sup> For example, as noted, MCFD reports that, in March 2022, there were 24,127 children and youth in the province in receipt of individualized autism funding payments.

<sup>79</sup> The case vignettes accurately reflect the experiences of the children and youth that the Representative becomes aware of through direct advocacy work and critical injury and death reviews. However, to protect the privacy and confidentiality of the young people and their families, some descriptive information has been withheld or modified or a composite has been created.

### Amanda's Story

Amanda is a 17-year-old who is curious about all types of animals, loves her Build-a-Bear creations and has a vivid imagination. She has a moderate intellectual disability as well as complex behaviours, which have increasingly included suicide attempts and ideation. Amanda will be eligible for CLBC services, although transition planning has not yet been initiated. She has been primarily raised by her dad as her mom struggles with mental health and substance use concerns and is often not able to be present for Amanda. She is very close to her dad, who is working hard to support her, but he is feeling very isolated and alone. He has asked for support from MCFD many times but hasn't felt like his concerns were being taken seriously – especially in the early years – and he was worried about child protection intervention if he pushed too hard.

Things began to unravel in the family about a year ago and Amanda was placed in two different staffed residential resources under a Special Needs Agreement (SNA). However, these placements broke down quickly as the staff were unable to respond effectively to Amanda's complex needs and challenging behaviours, which included repeated suicide attempts. As such, the SNA was cancelled and she returned to the family home. This is what Amanda wanted and, while her dad also wanted her to be home, he continued to express that he needed more support in order to make it work.

Since her return home, MCFD and the health authorities have not been able to provide adequate services to support her dad and to safely maintain Amanda at home. No other placement options are available should the family be unable to continue to care for her. Police are now regularly involved when Amanda becomes a significant risk to herself. She has been brought to the emergency department of her local hospital many times and, although there have been a number of apprehensions under the *Mental Health Act*, the hospital is typically reluctant to admit her. When she has been involuntarily admitted, the hospital staff have struggled to meet her needs and have often put her in seclusion and/or medically restrained her. The local hospital does not have the staff or appropriate space for proper care of a young person such as Amanda.

Previously, the Adolescent Psychiatric Units (APUs) operated by health authorities, as well as the Maples Adolescent Treatment Centre and Ledger House, have refused admittance due to Amanda's intellectual disability. Amanda is on the wait list for the Provincial Assessment Centre but that resource is not accepting any new patients exhibiting self-injurious or aggressive behaviors.

Amanda was recently admitted to hospital after another suicide attempt and refused treatment of her wounds. Amanda is soon to be 18 and the situation has not improved. The family is at a breaking point and faces service barriers everywhere they turn.

## Chris's Story

Chris is a 14-year-old, gender-fluid child of mixed European ancestry, who uses they/them pronouns and is exploring their gender identity and different ways to express themselves and be seen. Chris is artistic and loves to draw, paint, dress colourfully and change their hair colour weekly.

Chris experienced significant trauma in their first three years of life, before being adopted. It is suspected but not confirmed that they were prenatally exposed to alcohol and other substances. Their adoptive parents were very committed to Chris and understood that the transition would be difficult and that Chris could have attachment and developmental challenges due to the trauma they experienced. However, despite their intensive commitment to and love for Chris, they were overwhelmed by the responsibilities and challenges that they and Chris faced.

Chris has received multiple (and shifting) diagnoses including ASD, suspected FASD, obsessive compulsive disorder, ODD and ADHD. They struggle with self-regulation and have turned their frustration inward such that they engage in persistent and alarming non-suicidal self-injury, including cutting, self-strangulation and ingesting items ranging from batteries to nails. Some of Chris's injuries have necessitated hospital stays. Chris's parents have sought help and guidance since Chris was first adopted but decided 18 months ago that they could no longer cope. Their marriage was crumbling, they were worried about the impacts on their other children and they felt that they could not keep Chris safe. They signed an SNA with MCFD.

In the past 18 months, Chris has spent most of their time in and out of hospitals and medical facilities as the staffed residential resource that was created for them has been unable to sustain adequate and experienced staffing and respond effectively to Chris's challenging and escalating behaviours. The locked facility that Chris is currently in is also clear that it is not equipped to meet Chris's neuro-cognitive developmental needs as its focus is on mental health, not support needs. At this point, there is an impasse with no viable plan for Chris's care. Chris desperately wants to leave the facility and go home, but their parents have said that they can't have them home as they will not receive the support that they need.

RCY does have individual advocacy jurisdiction over children and youth with support needs, including those with neurodevelopmental conditions, in receipt of services from MCFD (but not from health authorities).<sup>80</sup> As with reports of critical injuries and deaths, RCY advocates working with these children and youth often encounter co-occurring mental health challenges and difficulties accessing appropriate services. The advocacy case vignette described below is an example of the typical challenges in accessing appropriate mental health services.

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<sup>80</sup> See s.1 and s.6 of the *RCY Act*. The Representative has requested that the Legislative Assembly's Select Standing Committee on Children and Youth, which is currently conducting a review of the *RCY Act*, consider filling this gap in jurisdiction.



## Joel's Story

Joel is a nine-year-old First Nations child who loves being outdoors, camping with his family, soccer and superhero comic books and movies – especially anything to do with Captain America. Joel has one older sibling, Jessie, who is just entering her final year of middle school. She loves to read, is quieter and more contemplative, and is very connected to her culture and maternal grandparents. Joel and Jessie's parents are very devoted to their children and have worked very hard to create a healthy home environment and positive, stable connection in their smaller community, despite having experienced significant challenges in their own childhoods and being moved frequently.

Joel has been diagnosed with ASD, ADHD and conduct disorder. He has been denied the opportunity to attend school for two years due to the school being unable to recruit and retain anyone to assist Joel when he is struggling to self-regulate. He sometimes expresses his frustrations through "aggressive outbursts" which the school says endanger himself and others. His mom has home-schooled him during this time, which has placed a significant strain on all members of the family, both emotionally and financially. Joel is increasingly isolated from his peers and community activities, despite his family's best efforts to help him stay connected and is now expressing sadness and becoming more critical and blaming of himself. Jessie is expressing anxiety and withdrawing from some of the activities she enjoys as she says that "people are blaming us for the way Joel is, even though he can't control himself sometimes."

Joel has been referred to CYMH several times and each time he and his family have been denied service. The family has been told by CYMH services that they think the issues are behavioural and that he "does not meet criteria." CYMH did not provide any further referrals or guidance for the family which was very distressing to the parents. Joel is not eligible for DDMH services due to his young age and likely won't be in the future as he does not have an ID diagnosis.

BC Children's Hospital (BCCH) has provided some psychiatric consultation and an inpatient stay there was considered but the family cannot afford the costs of travel and accommodation to be there with him, so the referral was not actioned. Current supports are a behavioural consultant and interventionist, and respite, although in their small community, access to these services is intermittent. In response to advocacy efforts, CYMH is re-assessing his eligibility for services as he has been displaying what may be additional mental health struggles.

## Conclusion and Recommendations

Children and youth with neurodevelopmental conditions experience significant challenges in their daily living due to the effects of their disability alone. The CHPC review, which applied rigorous Western scientific standards, confirms that there is an extraordinarily high prevalence of mental health challenges amongst these young people which obviously leads to compounding vulnerabilities and additional challenges in daily living for many of them, and for their caregivers. Fortunately, the review also confirms that there are opportunities to improve the health and circumstances of these children and youth – and their families – because there are mental health program services that are proven to be effective in ameliorating these challenges.

Yet, despite a number of reviews and reports that have called for improvements in services and despite government's major social policy initiatives of *A Pathway to Hope* and the CYSN Framework – together with a legislatively mandated government-wide accessibility plan – government has not stepped up by developing and implementing a specific plan to improve services for these highly vulnerable children. That plan should and must provide for comprehensive mental health screening, assessment and treatment services that are delivered by professionals who have the necessary training in co-occurring disorders. As well, services to Indigenous children need to be co-created and implemented with Indigenous communities.

Fortunately, there is a window of opportunity to fill this gap in service planning and implementation by way of government's recently announced reset of the CYSN Framework, the proposed consultation and co-creation process, and its commitment to new investments in services to under-served children and youth with support needs. Further, there is an opportunity to ensure that the work underway, in response to the RCY *Excluded* report, to develop and implement a plan to provide effective and accessible mental health services for children and youth with special needs, be aligned with priority actions of *A Pathway to Hope* and integrated into efforts underway to create a Child and Youth Substance Use and Wellness Framework to ensure that the needs of young people with co-occurring and complex conditions, such as mental health and substance use disorders and mental health disorders combined with neurodevelopmental conditions, are addressed.

## The Representative recommends:

1. MCFD to ensure that the CYSN Framework reset includes purposeful engagement with rights holders, Indigenous partners, service providers and families regarding mental health services for children and youth with support needs.

**Final engagement report to be completed by October 2024.**

2. MCFD ensure that as part of the CYSN Framework reset, that service delivery linkages and pathways for access to mental health services for children and youth with support needs are maximized in the Family Connection Centre pilots, and to ensure that the provision of these mental health services are formally included in the evaluation framework.

**Final evaluation report to be completed by March 31, 2025.**

3. Following the completion of the engagement and evaluation reports, MCFD to develop, implement and fully fund a plan to provide comprehensive mental health screening, assessment and effective treatment services for children and youth with support needs.

**Implementation to begin in April 2025.**

4. MMHA to coordinate, in collaboration with other relevant ministries and public bodies, comprehensive research to identify the prevalence of mental health disorders amongst children and youth with neurodevelopmental conditions to inform future service planning.

**Research to begin by April 2024.**

While this report and the appended CHPC report have shown that there is a need for improvement in data collection, these findings are not new and recommendations to address these issues have previously been made. The Representative therefore reiterates the recommendation from RCY's 2021 *Excluded* report, noting that timelines for necessary action have not been achieved to date:

5. The Ministry of Citizens' Services to initiate the development of a cross-ministry plan, in collaboration with MCFD, MoH, MMHA, MSDPR, and the Ministry of Education and Child Care, and in association with Indigenous Child and Family Service Agencies, health authorities and Community Living BC, to routinely collect high-quality demographic and service data that allows for disaggregation, providing an essential foundation for more effective policy development, program provision and service monitoring for children and youth with support needs and their families, who are receiving services from these public bodies.

NOTE: The Representative and her team are encouraged to see progress in legislation that will support the development of a provincial data plan to coordinate the use of data to advance equity, enhance insights and support reconciliation. However, the action steps proposed have not addressed how the legislative changes will be implemented to provide the essential foundation for more effective policy development, program provision and service monitoring.



# Addressing Mental Health Needs for Children with Neurodevelopmental Conditions

A Research Report

January 2023



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*At the Children’s Health Policy Centre, we acknowledge our privilege in being located on the ancestral lands of the xwməθkwəy’əm (Musqueam), Skwxwú7mesh (Squamish), Səl̓íl̓wətał (Tsleil-Waututh), q’íc’əy’ (Katzie) and kwikwəł̓ əm (Kwkwetlem) Nations. We understand and commit to the ongoing work of reconciliation that is required to honour all Indigenous Peoples.*

### **Citing this report**

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## Executive Summary

Neurodevelopmental conditions, including autism spectrum disorder (ASD), fetal alcohol spectrum disorder (FASD) and intellectual disabilities, begin very early in a child's life and are associated with characteristic challenges in daily living. As well as coping with these challenges, many children and their families also face concurrent mental disorders – and mental health care systems that often struggle to meet their needs.

To better address the mental health needs of children with neurodevelopmental conditions, policy-makers need high-quality data – including accurate prevalence estimates to inform service planning and evidence on effective treatments to ensure that these children receive interventions that work. This research report therefore aimed to identify (1) the prevalence of common mental disorders for children with ASD, FASD and intellectual disabilities; and (2) effective psychosocial treatments for common mental health concerns for these children.

The available prevalence data showed that the five most common childhood mental disorders overall – anxiety, attention-deficit/hyperactivity disorder (ADHD), oppositional defiant and conduct disorders, and depression – are much more prevalent for children with neurodevelopmental conditions. For example, estimated prevalence for any anxiety disorder was nearly eight times higher for children with ASD, estimated prevalence for ADHD was more than 14 times higher for children with FASD, and estimated prevalence of oppositional defiant and conduct disorders was nearly four times higher for children with intellectual disabilities. These findings suggest that for many children with neurodevelopmental conditions, mental disorders create additional needs – making access to effective treatments imperative.

This review found effective treatments for at least one mental health concern for all three neurodevelopmental conditions. Cognitive-behavioural therapy led to clinically meaningful reductions in anxiety disorder diagnoses and symptoms for children with ASD – across multiple studies. As well, parent training successfully reduced behaviour challenges for children with FASD and intellectual disabilities. We also found emerging evidence that social skills training helps children with FASD. These effective treatments need to be made readily available to all children who need them.

Mental health prevalence and intervention data can inform efforts to support the well-being of children with neurodevelopmental conditions. Next steps include ensuring that all children who have both neurodevelopmental and mental health conditions are identified early and receive timely treatment, and providing these children and their families with mental health resources proportionate to their needs. Services also need to be offered in ways that celebrate children's strengths and recognize their preferences, thereby meeting society's collective responsibility to ensure that all children can flourish and meet their potential.



## **I. Background**

### **I.1 When children have neurodevelopmental and mental health conditions**

Neurodevelopmental conditions – including autism spectrum disorder (ASD), fetal alcohol spectrum disorder (FASD) and intellectual disabilities – begin very early in a child’s life and are associated with characteristic challenges in daily living.<sup>1</sup> ASD includes difficulties with social communication and interactions and with repetitive patterns of interests or activities that interfere with a child’s ability to function at home, at school or in the community.<sup>1</sup> An FASD diagnosis is based on prenatal alcohol exposure at levels that result in neurodevelopmental concerns in at least three areas, including cognition, memory and executive functioning.<sup>2</sup> An intellectual disability diagnosis involves a child having significant challenges with both cognitive abilities and activities of daily living.<sup>1</sup>

Epidemiological surveys provide estimates of the proportion of children who have these three neurodevelopmental conditions. Estimated prevalence is 0.4% for ASD,<sup>3</sup> 0.8% for FASD,<sup>4</sup> and 1.2% for an intellectual disability diagnosis.<sup>5</sup> All these children need appropriate supports to ensure their flourishing – and all children with developmental conditions can flourish when appropriate supports are provided.<sup>6</sup>

Beyond coping with the challenges that come with developmental conditions, these children and their families must frequently cope with concurrent mental disorders.<sup>7</sup> The lives of children with both neurodevelopmental and mental health conditions can be considerably enhanced by effective interventions.<sup>7</sup> However, existing systems of care are often designed for “neurotypical” children and therefore fail to meet the mental health needs of children with neurodevelopmental conditions. For example, community mental health systems are often ill-equipped to assist these children and their families, resulting in needed interventions not being provided.<sup>7</sup> In addition, service delivery systems – including in British Columbia (BC) – have been criticized for being fragmented across agencies, programs and contractors, resulting in service gaps.<sup>8</sup> This criticism is made against the backdrop of mental health services that typically reach only about 44% of all children with mental disorders.<sup>3</sup>

To better address the mental health needs of children with neurodevelopmental conditions, policy-makers first need high-quality data. These data include accurate prevalence estimates, which are crucial for informing service planning; and evidence on effective mental health treatments for young people with ASD, FASD and intellectual disabilities, which is crucial to ensure that children receive interventions that work.

### **I.2 Goals of this research report**

This report therefore aimed to (1) to identify the prevalence of common mental disorders for children with ASD, FASD and intellectual disabilities; and (2) to identify effective psychosocial treatments for common mental health concerns for these children. In both cases, we aimed to identify the best available research evidence. The larger context is that of seeking to improve mental health for all children, including honouring children’s rights to receive the services they need when they need them.<sup>9</sup>

## 2. Methods

For this report, we conducted four systematic reviews using methods adapted from the *Cochrane Collaboration*.<sup>10</sup> The first review focused on the prevalence of concurrent mental disorders for children with ASD, FASD and intellectual disabilities. To meet our inclusion criteria, we required that relevant epidemiological data be reported in a systematic review with clearly described methods. As well, we required that most individual studies covered in the systematic reviews focus on children aged 18 years or younger and be conducted in high-income countries (for relevance to Canadian policy-making). Using this process, we identified 434 potentially relevant articles. We then selected the seven most rigorous systematic reviews to derive prevalence estimates.

Our other three systematic reviews addressed psychosocial treatments for concurrent mental health concerns for children with ASD, FASD and intellectual disabilities. We focused on psychosocial interventions, since these are usually first-line treatments for the most common childhood mental disorders.<sup>11</sup> Specifically, for children with these neurodevelopmental conditions, we searched for randomized controlled trials (RCTs) evaluating treatments for anxiety, attention-deficit/hyperactivity (ADHD), oppositional defiant, substance use, conduct and major depressive disorders, given that these are the most prevalent childhood mental disorders. (However, given the purpose of this report, we did not seek RCTs on interventions aiming to treat core symptoms associated with the three neurodevelopmental conditions of interest, such as behavioural interventions for children with ASD.) The Appendices provide more information on our search processes and inclusion criteria for the three treatment reviews.

Our searches identified more than 1,600 potentially relevant treatment articles. After title screening, two authors independently assessed all relevant abstracts. Applicable studies were then retrieved and independently assessed, again by two authors. Following these steps, we identified 20 RCTs that met all inclusion criteria: 12 RCTs evaluating nine interventions for children with ASD; three RCTs evaluating four interventions for children with FASD; and five RCTs evaluating four interventions for children with intellectual disabilities. We extracted and summarized data for all 20 RCTs, again with independent verification by a second author. At every stage, any differences were resolved by consensus among the larger team.

This report is based on research evidence drawn from epidemiological surveys for estimating prevalence and from RCTs for assessing treatments. We required systematic reviews for the prevalence data because this approach combines data from several studies, which can result in more precise estimates than those derived from single studies.<sup>12</sup> We also required RCTs for the treatment data because this approach is recognized as providing particularly rigorous evidence for evaluating the effectiveness of health interventions.<sup>10, 13</sup> We nevertheless acknowledge that these methodologies have limitations, including under-representing Indigenous Peoples, methods and perspectives.<sup>14-15</sup> More studies are needed that are designed for and about Indigenous children and that are led by Indigenous Peoples – informed by Traditional Knowledge as well as Western scientific methods.

## 3. Findings

### 3.1 Mental disorders in children with neurodevelopmental conditions

We identified prevalence data for five of the most common mental disorders – which in aggregate represent a substantial proportion of all children who have these conditions. For children with ASD and for children with intellectual disabilities these disorders included anxiety, ADHD, oppositional defiant disorder, conduct disorder and depression. (For children with ASD, rather than reporting separate prevalence for oppositional defiant and conduct disorders, systematic review authors reported the proportion of children having either condition.)<sup>16</sup> For children with FASD, we identified prevalence data that meet our inclusion criteria for four of the most common mental disorders, lacking only data for anxiety.

For children with neurodevelopmental conditions, estimated prevalence of each of the five mental disorders exceeded that for the general population of children – with many differences being substantial, as shown in Table 1. For example, estimated prevalence for any anxiety disorder was nearly eight times higher for children with ASD compared with the general population of children,<sup>3, 17</sup> while estimated prevalence of ADHD was more than 14 times higher for children with FASD.<sup>3, 18</sup> As well, the estimated prevalence for major depressive disorder was more than eight times higher for children with ASD and nearly 28 times higher for children with FASD, compared with the general population.<sup>3, 19–20</sup> While differences in estimated prevalence for children with intellectual disabilities were less extreme relative to the general population, rates of oppositional defiant and conduct disorders were still nearly four times higher while ADHD was more than double and major depressive disorder nearly double.<sup>3, 21–22</sup>

**Table 1. Estimated prevalence of mental disorders for children with neurodevelopmental conditions**

Disorder	Autism spectrum disorder	Fetal alcohol spectrum disorder	Intellectual disability	General population* <sup>3</sup>
Any anxiety disorder	39.6% <sup>17</sup>	—	5.4%* <sup>22</sup>	5.2%
Attention-deficit/hyperactivity disorder	34.8% <sup>† 16</sup>	52.9%* <sup>18</sup>	9.5%* <sup>† 21</sup>	3.7%
Oppositional defiant disorder	12.6% <sup>‡ 16</sup>	12.9%* <sup>18</sup>	12.4%* <sup>† 21</sup>	3.3%
Conduct disorder		7.0%* <sup>18</sup>	5.1%* <sup>† 21</sup>	1.3%
Major depressive disorder	10.6% <sup>19</sup>	36.0%* <sup>20</sup>	2.5%* <sup>22</sup>	1.3%

— Data not available

\* Most study participants were ≤ 18 years but some adults were included.

† Prevalence calculated based on data provided in the systematic review.

‡ Prevalence included both oppositional defiant and conduct disorders.

## 3.2 Mental health treatments for children with autism spectrum disorder

We accepted 12 RCTs evaluating 9 mental health interventions for children with ASD.<sup>23-35</sup> All focused on treating anxiety. In 11 studies, all children met criteria for an anxiety disorder,<sup>23-32, 34-35</sup> while in the remaining study, most children did.<sup>33</sup> All 12 studies evaluated the effectiveness of cognitive-behavioural therapy (CBT) in young people ranging in age from six to 18 years. Eleven studies used CBT to treat a variety of conditions including separation anxiety, social anxiety and generalized anxiety disorders as well as specific phobias. The remaining study examined CBT's effectiveness with specific phobias only.<sup>30</sup>

CBT typically involved several elements: (1) educating families about anxiety; (2) coaching children to reduce physical symptoms of anxiety using techniques such as deep breathing; (3) teaching children to challenge unrealistic anxious thinking; and (4) supporting children to practise being in fear-provoking situations while managing their anxiety.<sup>31</sup> Most CBT programs were originally designed for typically developing children and then modified, for example, by using more visual materials and more concrete language to better accommodate learning styles of children with ASD.<sup>34</sup> As well, some programs included specific content to better address the needs of children with ASD, such as components on developing social skills.<sup>27, 35</sup>

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**Estimated prevalence for any anxiety disorder was nearly eight times higher  
for children with autism spectrum disorder.**

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CBT proved highly successful for treating anxiety in children with ASD. Of nine RCTs examining diagnostic outcomes, eight showed statistically significant reductions on a least one diagnostic measure by the end of treatment.<sup>24, 26-27, 29, 31-34</sup> All 12 programs also successfully reduced anxiety symptoms according to one or more measures. As well, even though the interventions focused on anxiety, many produced other positive outcomes, including reducing behaviour problems<sup>23, 29, 33</sup> and core ASD symptoms,<sup>27-29</sup> as well as improving daily living skills.<sup>26, 33</sup>

Beyond reporting on statistical significance, many studies also provided data on effect sizes, indicating the degree to which the intervention made a meaningful difference in children's lives. Seven programs produced large effect sizes for anxiety symptom outcomes: Family-based Exposure-focused Treatment, Building Confidence, Behavioural Intervention for Anxiety in Children with Autism (BIACA), Blue Room Virtual Reality Environment, Facing Your Fears, Brave Online and Coping Cat.<sup>23, 26-32, 34</sup> Moreover, for three of these programs – BIACA, Facing Your Fears and Coping Cat – effect sizes for the diagnostic reductions were also large.<sup>27, 31, 34</sup> Table 2, on the next page, summarizes these 12 RCTs and their findings.

**Table 2. Studies of mental health treatments for children with autism spectrum disorder**

Program name	Program components*	Ages (years)	Duration	Follow-up	Outcomes (effect sizes)
<b>Goal: Reduce anxiety</b>					
Family-based Exposure-focused Treatment <sup>†23</sup>	CBT (child + parent)	6–17	12 weeks	None	NR primary anxiety diagnosis (14.3% vs 100%) ↓ 5 of 6 anxiety symptoms ( $d = 0.84$ – $1.22$ ) ↓ 1 of 1 emotional problems ( $d = 0.84$ ) ↓ 1 of 1 behavioural problems ( $d = 0.79$ )
Building Confidence <sup>24</sup>	CBT (child + parent)	7–11	32 weeks	None	↓ primary anxiety diagnoses (28.6% vs 100%) ↓ 1 of 1 anxiety symptoms
Building Confidence <sup>25–26</sup>	CBT (child + parent)	7–11	16 weeks	None	↓ any anxiety diagnoses (47.1% vs 91.3%) ↓ 3 of 4 anxiety symptoms ( $d = 1.23$ – $2.46$ ) ↑ 1 of 1 daily living skills ( $d = 0.45$ )
Behavioural Intervention for Anxiety in Children with Autism (BIACA) <sup>‡27</sup>	CBT (child + parent)	7–11	16 weeks	None	↓ primary anxiety diagnosis (62.5% vs 95.2%; $d = 1.37$ ) ↓ 6 of 10 anxiety symptoms ( $d = 0.63$ – $1.59$ ) ↓ 1 of 1 emotional problems ( $d = 0.56$ ) X 1 of 1 behavioural problems
BIACA <sup>‡28</sup>	CBT (child + parent)	11–15	16 weeks	None	X primary anxiety diagnoses (68.4% vs 78.6%) ↓ 2 of 4 anxiety symptoms ( $g = 0.74$ ; OR = 9.38) X 1 of 1 emotional problems
BIACA <sup>‡29</sup>	CBT (child + parent)	11–16	16 weeks	None	↓ primary anxiety diagnosis (62.5% vs 100%) ↓ 5 of 6 anxiety symptoms ( $d = 0.59$ – $1.30$ ) X 2 of 2 emotional problems ↓ 1 of 1 behavioural problems ( $d = 0.63$ ) ↓ 1 of 5 anxiety symptoms ( $d = 1.03$ )
Blue Room Virtual Reality Environment <sup>30</sup>	CBT (child)	7–14	2 weeks	2 weeks 6 months	↓ 1 of 5 anxiety symptoms ( $d = 1.14$ )
Facing Your Fears <sup>31</sup>	CBT (child + parent group)	7–14	12–16 weeks	None	↓ primary anxiety diagnoses ( $d = 0.71$ ) ↓ 2 of 3 anxiety symptoms ( $d = 0.66$ – $1.03$ )
Brave Online <sup>32</sup>	CBT (child + parent)	8–12	16 weeks	None	X primary anxiety diagnosis (81% vs 100%) X any anxiety diagnosis (90.5% vs 100%) ↓ # of anxiety diagnoses ( $d = 2.72$ ) ↓ 4 of 4 of anxiety symptoms ( $d = 0.71$ – $2.00$ ) ↓ 1 of 1 emotional problems ( $d = 0.91$ )
Secret Agent Society: Operation Regulation <sup>33</sup>	CBT (child)	8–12	10–14 weeks	None	↓ # of anxiety diagnoses ( $d = 0.61$ ) ↓ 2 of 3 anxiety symptoms ( $d = 0.57$ – $0.60$ ) ↓ 1 of 3 emotional problems ( $d = 0.58$ ) ↑ 1 of 2 emotion regulation ( $d = 0.79$ ) ↓ 1 of 3 behavioural problems ( $d = 0.52$ ) ↑ 1 of 4 daily living skills ( $d = 0.71$ )
Coping Cat <sup>34</sup>	CBT (child)	8–14	16 weeks	None	↓ primary anxiety diagnoses (41.7% vs 100%; NNT = 1.72) ↓ # of concurrent diagnoses ( $d = 1.22$ ) ↓ 2 of 3 anxiety symptoms ( $d = 1.17$ – $1.35$ )
Multimodal Anxiety and Social Skill Intervention <sup>†35</sup>	CBT (child group + individual)	12–18	Not reported	None 12 weeks	NR any anxiety diagnoses (71.1% vs 69.1%) <sup>§</sup> ↓ 1 of 2 anxiety symptoms <sup>**</sup> NR any anxiety diagnoses (82.2% vs 58.2%) <sup>††</sup> X 0 of 2 anxiety symptoms

CBT = cognitive-behavioural therapy; NR = statistical significance not reported; ↓ or ↑ = statistically significant improvements;  $d$  = Cohen's  $d$ ; X = no statistically significant difference;  $g$  = Hedges'  $g$ ; OR = odds ratio; NNT = number needed to treat

\* Individual delivery unless noted; † No significant difference for ASD symptoms; ‡ Significant reductions for ASD symptoms; § No statistically significant group differences for 3 assessed disorders (social or generalized anxiety or specific phobia); comparison children had significantly fewer separation anxiety diagnoses.

Percentages include children having any of the 4 disorders; \*\* 1 symptom outcome tested separately for 4 anxiety disorders; symptom reduction significant for social anxiety disorder only; †† No statistically significant difference for any of 4 assessed disorders.

### 3.3 Mental health treatments for children with fetal alcohol spectrum disorder

We accepted three RCTs evaluating four mental health treatments for children with FASD.<sup>36-39</sup> (One RCT evaluated two different interventions.)<sup>36</sup> Child participants ranged in age from five to 12 years. Three interventions – GoFAR, FACELAND and the Alert Program (for Self-Regulation) – focused on improving self-regulation for children with behaviour challenges. GoFAR and FACELAND both involved parent training, which included teaching parents strategies to calm their children and to address negative behaviours as well as techniques for helping children learn life skills.<sup>36</sup> Both interventions also included cognitive training sessions for children and parents, focused on using planning and reflection in challenging situations. As well, two of the three interventions focused on executive functioning skills, which include problem-solving and self-regulation abilities.<sup>36-37</sup> Specifically, GoFAR taught children to plan and reflect while playing a challenging computer game,<sup>36</sup> while the Alert Program taught children to regulate emotions and activity levels through self-awareness and practice.<sup>37</sup> FACELAND included emotion-recognition training which involved rewarding children for correctly identifying the emotions of computer game characters.<sup>36</sup>

The fourth intervention – Child Friendship Training – focused on improving social skills using a group training program adapted for children with FASD.<sup>38</sup> Children were taught rules for social interactions as well as specific skills, including starting conversations, joining groups and dealing with conflicts.<sup>38</sup> Parents participated in a concurrent group to support their children’s skill development.<sup>38</sup>

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#### Mental disorders are causing a pronounced burden for children with neurodevelopmental conditions, compared with other children.

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Two of three programs aiming to improve self-regulation for children with behaviour challenges showed success. Both GoFAR and FACELAND reduced behaviour problems.<sup>36</sup> In addition to being statistically significant, children’s gains were clinically meaningful as shown by large effect sizes (partial  $\eta^2 = 0.24$ ) compared to controls (for both programs). In contrast, the Alert Program made no meaningful differences for behaviour, emotional or attention problems; social skills; emotion recognition; or understanding social situations.<sup>37</sup> The program did improve executive functioning but only on one measure out of six.

Child Friendship Training also showed some success.<sup>39</sup> Specifically, the program improved children’s social skills, reduced behaviour and emotional problems and reduced perceptions of hostile intentions in ambiguous situations – all with moderate clinical effects. Children’s social skills knowledge also improved with large clinical effects.<sup>39</sup> Table 3, on the next page, summarizes these four RCTs and their findings.

**Table 3. Studies of mental health treatments for children with fetal alcohol spectrum disorder**

Program name	Program elements*	Ages (years)	Duration	Follow-up	Outcomes (effect sizes)
<b>Goal: Improve self-regulation</b>					
GoFAR	Executive functioning skills training† (child) Parent training Cognitive training (child + parent)	5–10	10 weeks	None	↓ 1 of 1 behavioural problems
FACELAND <sup>36</sup>	Emotion recognition training (child) Parent training Cognitive training (child + parent)	5–10	10 weeks	None	↓ 1 of 1 behavioural problems
Alert Program for Self-Regulation <sup>37</sup> 🇨🇦	Executive functioning skills training‡ (child)	8–12	14 weeks	None	X 1 of 1 behavioural + emotional problems X 2 of 2 attention problems ↑ 1 of 6 executive functioning X 1 of 1 social skills X 1 of 1 emotion recognition X 4 of 4 understanding of social situations
<b>Goal: Improve social skills</b>					
Child Friendship Training <sup>38–39</sup>	Social skills training (child + parent groups)	6–12	12 weeks	None	↑ 1 of 2 social skills ( $d = 0.52$ ) ↓ 1 of 2 behavioural + emotional problems ( $d = 0.40$ ) ↓ 1 of 2 perceiving hostile intentions in ambiguous situations ( $d = 0.42$ ) ↑ 1 of 1 social skills knowledge ( $d = 1.28$ )

↓ or ↑ = statistically significant improvements; X = no statistically significant difference;  $d$  = Cohen's  $d$

\* Individual delivery unless noted; † Included teaching children to plan and reflect; ‡ Including teaching children self-awareness skills

### 3.4 Mental health treatments for children with intellectual disabilities

We accepted five RCTs evaluating four mental health interventions for children with intellectual disabilities.<sup>40–45</sup> Child participants ranged in age from three to 18 years. Three RCTs evaluated two interventions for addressing behavioural challenges: Parent-Child Interaction Therapy (PCIT) (one RCT); and Stepping Stones Triple P (Triple P) (two RCTs, including one comparing basic and enhanced versions of the program).<sup>40–42</sup>

Both PCIT and Triple P used parent training.<sup>40–42</sup> For PCIT this included providing the standard program, developed for neurotypical children without adaptation, which involved teaching parents to establish nurturing relationships with their children while setting consistent limits.<sup>40</sup> In contrast, Triple P was adapted for children with an intellectual disability by adding components to the standard program on families' adjustment to having a child with this diagnosis. This included teaching parents strategies to promote their child's competence and development as well as managing challenging behaviours.<sup>41–42</sup> Enhanced Triple P included a coping skills training program for parents – focused on working collaboratively with professionals, strengthening social supports, and learning effective CBT-based techniques such as relaxation and challenging unhelpful thinking.<sup>41</sup>

The third intervention – Training Attention and Learning Initiative – focused on helping children with attention problems.<sup>43</sup> This computerized program included games designed to improve children’s selective and sustained attention, for example, by locating target objects that differed in size and colour from non-target objects.<sup>43</sup>

The fourth intervention – Cognitive Bias Modification Training for Interpretation (CBMTI) – attempted to reduce children’s social anxiety.<sup>45</sup> In this program, children were presented with very short stories describing social situations – both verbally and in writing – with one word missing in the final sentence. The missing word was then presented separately, resulting in the story having a positive ending, such as other students liking the child’s presentation.<sup>45</sup>

Both parent training programs showed positive results. PCIT reduced child behaviour problems with a moderate clinical impact at the end of treatment.<sup>40</sup> Similarly, the basic and enhanced Triple P evaluation both showed reduced child behaviour problems at the end of treatment.<sup>41</sup> The other Triple P evaluation also showed reductions on a combined measure of behavioural and emotional problems at the end of treatment but not at six-month follow-up.<sup>42</sup>

The Training Attention and Learning Program produced only modest results. Specifically, children showed significant gains on one of seven attention measures, with small clinical effects at the end of treatment and at six-week follow-up.<sup>44</sup> At six-week follow-up, children also showed significant gains on one of nine measures of executive functioning, namely, a planning and organizing task. However, the program made no significant difference for children’s behaviour or anxiety symptoms.<sup>44</sup>

CBMTI successfully reduced children’s anxiety symptoms as well as their perceptions of negative evaluations in ambiguous situations – both with moderate clinical effects.<sup>45</sup> Table 4, on the next page, summarizes all five RCTs and their findings.

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**For children with intellectual disabilities and concurrent behaviour challenges,  
parent training programs showed evidence of success,  
particularly for parents of preschoolers.**

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**Table 4. Studies of mental health treatments for children with intellectual disabilities**

Program name	Program elements*	Ages (years)	Duration	Follow-up	Outcomes (effect sizes)
<b>Goal: Reduce disruptive behaviours</b>					
Parent-Child Interaction Therapy <sup>40</sup>	Parent training	3–6	12 weeks	None	↓ 1 of 1 behavioural problems ( $d = 0.67$ )
Stepping Stones Triple P	Parent training	<6	10–16 weeks	None	↓ 3 of 4 behavioural problems
Stepping Stones Triple P Enhanced <sup>41</sup>	Parent training Coping skills training (parent)	<6	10–16 weeks	None	↓ 3 of 4 behavioural problems
Stepping Stones Triple P <sup>42</sup>	Parent training	5–12	10–12 weeks	None 6 months	X 1 of 1 behavioural problems ↓ 1 of 2 behavioural + emotional problems X 1 of 1 behavioural problems X 2 of 2 behavioural + emotional problems
<b>Goal: Reduce attention problems</b>					
Training Attention and Learning Initiative <sup>43–44</sup>	Attention training (child)	4–11	5 weeks	None 6 weeks	↓ 1 of 7 attention problems ( $d = 0.24$ ) X 4 of 4 behavioural problems X 1 of 1 anxiety symptoms X 9 of 9 executive functioning ↓ 1 of 7 attention problems ( $d = 0.26$ ) X 4 of 4 behavioural problems X 1 of 1 anxiety symptoms ↑ 1 of 9 executive functioning
<b>Goal: Reduce social anxiety</b>					
Cognitive Bias Modification Training for Interpretation (CBMTI) <sup>45</sup>	Cognitive training (child)	12–18	3 weeks	10 weeks	↓ 1 of 1 of anxiety symptoms ( $\eta^2 = 0.11$ ) ↓ 2 of 2 perceiving negative social evaluation in ambiguous situations ( $\eta^2 = 0.14–0.15$ )

↓ or ↑ = statistically significant improvements; X = no statistically significant difference;  $d$  = Cohen's  $d$

\* Individual delivery unless noted

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All children who have both neurodevelopmental and mental health conditions  
need to be identified early and receive timely treatment.

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## 4. Discussion

### 4.1 Summary

According to this review, among children with neurodevelopmental conditions, the five mental disorders of focus – anxiety, ADHD, oppositional defiant and conduct disorders and depression – are much more common than in the general population of children. For example, estimated prevalence for any anxiety disorder was nearly eight times higher for children with ASD,<sup>3, 17</sup> while estimated prevalence of ADHD for children with FASD was more than 14 times higher.<sup>3, 18</sup> As well, the estimated prevalence for major depressive disorder was more than eight times higher for ASD and nearly 28 times higher for children with FASD, compared with other children.<sup>3, 19-20</sup> Although differences for children with intellectual disabilities were less marked, rates of conduct disorder were still nearly four times higher than in the general population of children.<sup>3, 21</sup> These findings suggest that mental disorders are causing a pronounced burden for children with neurodevelopmental conditions, compared with other children.

The high prevalence of mental disorders for children with neurodevelopmental conditions means that it is crucial that they can access effective mental health treatments when they need them. Regarding such treatments, we found considerable research evidence showing that CBT is highly successful for children with ASD who also have anxiety concerns. Most studies found that CBT reduced anxiety diagnoses and symptoms to a degree that was clinically meaningful.<sup>23, 26-32, 34</sup> As well, CBT was effective for young people with ASD from the early school years to the teens.<sup>23, 29</sup>

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**Children with neurodevelopmental conditions  
should be provided with resources proportionate to their needs.**

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For children with FASD who also have behaviour challenges, multicomponent interventions showed some success. These interventions included parent training coupled with cognitive training for both parents and children.<sup>36</sup> As well, evidence is emerging on the effectiveness of programs to help children with FASD to improve their social skills.<sup>39</sup> For children with intellectual disabilities and concurrent behaviour challenges, parent training programs showed evidence of success, particularly for parents of preschoolers.<sup>40-42</sup> However, there was only modest evidence supporting cognitive training to reduce social anxiety in this population of young people, and only limited evidence supporting attention training. For children with ASD, FASD and intellectual disabilities who also have mental health concerns, more high-quality research is clearly needed – evaluating interventions for a broader range of mental disorders, including major depressive disorder. Yet the available evidence shows that effective treatments do exist. These effective treatments need to be made readily available to all children with developmental conditions, while more research is undertaken.

## **4.2 Policy and practice implications**

### *Recognize and address the high mental health burdens for children with neurodevelopmental conditions*

Our review suggests that children with ASD, FASD and intellectual disabilities face substantially higher rates of mental disorders than children in the general population. Consequently, publicly funded children's mental health services need to provide additional attention and resources to these children and their families at levels that are proportionate to the needs. Children with neurodevelopmental conditions, along with their families, are already coping with many challenges. It is imperative that they be provided with adequate mental health care to meet their needs.

### *Ensure timely access to effective treatments*

There is strong research evidence supporting CBT to treat anxiety disorders for children with ASD. This evidence is particularly compelling given that nearly 40% of children with ASD experience these disorders.<sup>17</sup> As well, emerging evidence suggests that parent training can reduce behaviour problems for children who have FASD or intellectual disabilities. Effective treatments for these concerns are particularly important since behaviour disorders are four and five times higher for children with FASD and intellectual disabilities, respectively, compared with the general population of children.<sup>3, 18, 46</sup>

Recognizing the benefits of CBT and parent training, many jurisdictions have increased their availability – and many practitioners working with typically developing children already deliver these interventions, including in BC.<sup>47-50</sup> These efforts could be enhanced to ensure full inclusion of children with neurodevelopmental conditions within existing mental health care systems. In addition, all children who have both neurodevelopmental and mental health conditions need to be identified early and receive timely treatment. Asking them to wait adds yet another obstacle that is avoidable.

### *Make mental health care systems more responsive to children with neurodevelopmental disorders*

Beyond ensuring that children with neurodevelopmental conditions receive effective and timely treatments for their mental health needs, the mental health care systems serving these children and their families need to be more responsive. For example, practitioners can receive training to enhance their knowledge and skills in delivering mental health treatments to these children and families.<sup>8</sup> As well, it may be beneficial to designate practitioners with specialized training in working with children with neurodevelopmental disorders to provide their mental health treatment – mirroring approaches taken for treating concurrent substance use and other mental health concerns in young people.<sup>8</sup>

### *Increase the mental health care options for children with neurodevelopmental conditions*

While there is considerable high-quality research evidence on effective treatments for childhood mental disorders generally,<sup>11</sup> far fewer interventions have been evaluated for children with neurodevelopmental conditions. The lack of research on treating major depressive disorder for children with ASD, FASD and intellectual disabilities is particularly concerning, given its high prevalence for these populations. Still the available evidence revealed a crucial finding. Effective treatments identified for anxiety and behaviour concerns mirrored those with proven success for typically developing children – and were successfully delivered to children with neurodevelopment conditions without adaptations.<sup>32, 40</sup>

Our findings can inform the development of new mental health interventions for children with neurodevelopmental conditions. Specifically, given evidence from the general population supporting parent training for ADHD, CBT for depression, and multicomponent interventions for substance use disorders, these interventions should be assessed for children with neurodevelopmental disorders.<sup>11</sup> For example, we found less rigorous yet promising studies supporting a multicomponent intervention to reduce alcohol use for teens with FASD who were light-to-moderate drinkers,<sup>51</sup> and supporting CBT to reduce depressive symptoms for teens with ASD.<sup>52</sup> Building on such results is a way to increase the treatment options for children with neurodevelopmental conditions.

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**Services need to be offered in ways that  
celebrate children’s strengths and recognize their preferences.**

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### *Prevent mental health problems and meet children’s basic needs*

Preventing childhood mental disorders can avert unnecessary distress, symptoms and diagnoses while also encouraging healthy development. Many effective prevention interventions have been designed for typically developing children – addressing anxiety, ADHD, oppositional defiant and conduct disorders, substance use disorders, depression, eating disorders and posttraumatic stress.<sup>11</sup> Children with neurodevelopmental conditions also need access to effective prevention programs, so new studies need to be conducted for and with these young people too. Alongside prevention, it is crucial to ensure that all children’s basic needs are met, and to protect all children from avoidable adversities that can contribute to the development of mental disorders, including socio-economic disadvantage, parent mental health problems and child maltreatment.

Children with neurodevelopmental conditions should be provided with resources proportionate to their needs. Providing effective interventions for their mental health concerns is paramount. Services also need to be offered in ways that celebrate children’s strengths and recognize their preferences,<sup>7</sup> thereby meeting society’s collective responsibility to ensure that all children can flourish and meet their potential.<sup>6</sup>

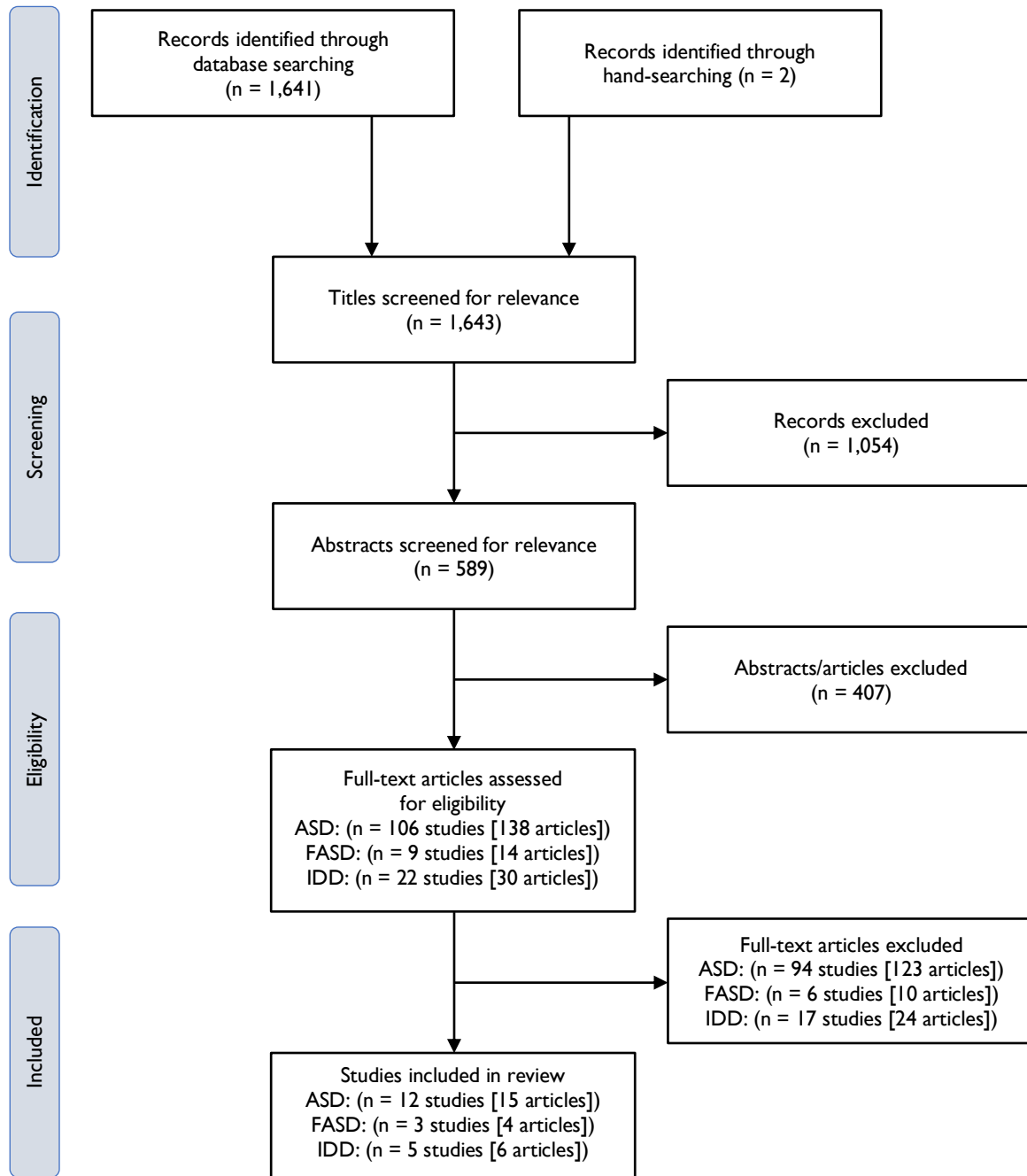
## 5. Appendices

### 5.1 Review methods

**Table A1. Search strategy**

Databases	<ul style="list-style-type: none"><li>• CINAHL, ERIC, Medline and PsycINFO</li></ul>
Search Terms	<ul style="list-style-type: none"><li>• Asperger syndrome, autism, autism spectrum disorders, ASD, fetal alcohol spectrum disorder, FASD, fetal alcohol syndrome, intellectual developmental disorder, IDD, intellectual disability or pervasive developmental disorder; and</li><li>• Anxiety, anxiety disorders, attention deficit disorder, attention deficit disorder with hyperactivity, ADHD, behaviour disorders, conduct disorder, depressive disorder, disruptive behaviour disorders, major depression, mood disorder, oppositional defiant disorder, substance use disorder or substance-related disorder; and</li><li>• Prevention, intervention or treatment</li></ul>
Limits	<ul style="list-style-type: none"><li>• Peer-reviewed articles published in English through until October 2022</li><li>• Child participants aged 18 years or younger</li><li>• Randomized control trial methods used</li></ul>

**Figure A1. Search process for randomized controlled trials\***



\* Adapted from Preferred Reporting Item for Systematic Reviews and Meta-Analyses<sup>53</sup>

**Table A2. Inclusion criteria for mental health treatment studies\***

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▪ Studies focused on evaluating interventions in children ≤18 years
▪ Interventions aimed to treat mental health concerns <sup>†</sup> for children with autism spectrum disorder (ASD), fetal alcohol spectrum disorder (FASD) or intellectual disabilities (ID) <sup>‡</sup>
▪ Interventions were evaluated in high-income countries for applicability to Canadian policy
▪ Interventions fell within scope of delivery for children’s mental health practitioners or for self-delivery
▪ Participants were randomly assigned to intervention or comparison groups (i.e., no intervention, active control or usual care)
▪ Clear descriptions were provided of participant characteristics, settings and interventions
▪ Outcome indicators included mental health diagnostic or symptom measures
▪ Outcome measures <ul style="list-style-type: none"><li>▪ ASD — completed by two or more informants, e.g., child, parent or teacher, at least one of whom was blinded to participant’s group assignment</li><li>▪ FASD and ID — completed by one or more informants who was not required to be blinded<sup>§</sup></li></ul>
▪ Reliability and validity were documented for primary outcome measures or ≥50% of items addressed behavioural and/or emotional problems
▪ Level of statistical significance was reported for primary outcomes measures <sup>**</sup>
▪ Attrition rates were ≤20% at final assessment and/or intention-to-treat analyses were used

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\* Mental health concerns included anxiety, attention-deficit/hyperactivity, oppositional defiant, substance use, conduct and depressive disorder diagnoses or symptoms.

† For children with ASD, we required that participants have mental health diagnoses at the start of the study; however, for children with FASD and ID, we only required that participants have elevated mental health symptoms, not diagnoses, because of the limited number of studies.

‡ All children were diagnosed with ASD or FASD/partial FASD or alcohol-related neurodevelopmental disorder or ID at study outset; most children were also experiencing behavioural or emotional problems (or diagnoses) at study outset.

§ Standards were lower for FASD and ID because so few treatment studies for these children included multiple outcome sources or blinding.

\*\* Studies were excluded where authors indicated insufficient power to detect group (intervention/control) differences.

## 5.2 Research terms explained

Policy-makers need high-quality evidence about whether a given intervention works to help children.

**Randomized controlled trials** (RCTs) are a particularly rigorous method for assessing intervention effectiveness. In RCTs, participants are randomly assigned to intervention or control groups. Randomizing participants – that is, giving everyone an equal likelihood of being assigned to a given group – helps to ensure that the intervention is the only difference between the groups. In turn, this process provides confidence that any benefits are due to the intervention rather than due to chance or other factors.

To determine whether an intervention provides benefits, researchers analyze relevant outcomes. If an outcome is **statistically significant**, it helps provide certainty the intervention was effective rather than appearing that way due to chance. The studies included in this report used the typical convention of having at least 95% confidence that results reflected the intervention’s real impact. As well, some included studies determined whether the intervention was clinically meaningful by assessing the degree of difference the intervention made in the young person’s life. This was achieved by calculating outcome **effect sizes**, which provide a quantitative measure of the strength of the relationship between the intervention and the outcome. The studies we included reported a variety of effect sizes, as described below.

- Cohen’s *d* and Hedges’ *g* have the following standard interpretations: 0.2 = small effect; 0.5 = moderate effect; and 0.8 = large effect.
- Odds ratio indicates the increased or reduced odds of an outcome occurring, for example, having nine times higher odds of reduced anxiety symptoms after participating in cognitive-behavioral therapy.
- Number needed to treat indicates the number of children needed to treat to avoid one additional negative outcome. For example, an NNT of 2 means that you have to treat two children with cognitive-behavioural therapy to have one no longer meet criteria for an anxiety disorder.
- Partial  $\eta^2$  has the following standard interpretations: 0.01 = small effect; 0.06 = medium effect; and 0.14 = large effect.



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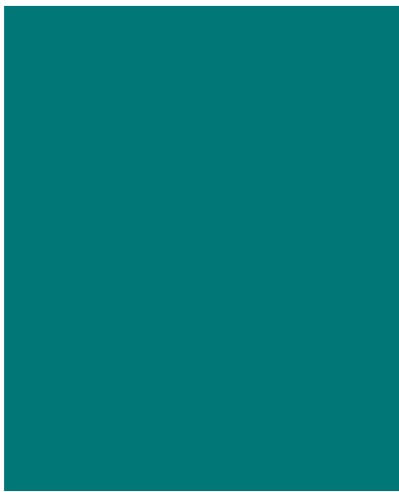
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