

Don't Look Away: Issues Spotlight

Too Many Left Behind: Ensuring Children and Youth with Disabilities Thrive

RC&Y

Representative
for Children & Youth

January 2025

The Representative and staff, working 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 Lekwungen (place to smoke herring) people of the Songhees and Esquimalt Nations (Victoria) where our offices are located. We also acknowledge our Métis and Inuit partners and friends living in these beautiful territories.



January 29, 2024

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 *Too Many Left Behind: Ensuring Children and Youth with Disabilities Thrive* to the Legislative Assembly of British Columbia.

This report is prepared in accordance with Section 6(b) of the Representative for Children and Youth Act which gives the Representative authority to monitor, review, audit and conduct research on the provision of a designated service by a public body or director for the purpose of making recommendations to improve the effectiveness and responsiveness of that service, and comment publicly on any of these functions.

Sincerely,

A handwritten signature in black ink, appearing to read "J Charlesworth". The signature is fluid and cursive, with a long horizontal stroke at the end.

Dr. Jennifer Charlesworth
Representative for Children and Youth

pc: Ms. Kate Ryan-Lloyd
Clerk of the Legislative Assembly
Chair, Select Standing Committee for Children and Youth
Deputy Chair, Select Standing Committee for Children and Youth

**The time to act
for children
and youth with
disabilities
is now.**



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Contributors

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Acknowledgements

The Representative extends heartfelt gratitude to the over 90 families and caregivers who participated in personal interviews and the more than 1,160 families and caregivers who completed the RCY check-in survey. These parents, family members, and caregivers generously shared their experiences and perspectives, bringing this report to life and strengthening our resolve to advocate for the critical changes that are so urgently needed.

The RCY is also grateful to the many dedicated organizations whose knowledge, perspectives and insights have enriched our understanding of the lived and living experiences of children and youth with disabilities and their families.

Aboriginal Infant Development Program
Aboriginal Supported Child Development
ADHD Advocacy Society of BC
ARC Programs – Kelowna Family Connections Centre
Asante FASD and Neurodevelopmental Services
Autism Community Training – ACT
Autism Support Network of BC
Autism BC
BC Aboriginal Child Care Society
BC Aboriginal Network on Disability Society
BC Association of Aboriginal Friendship Centres
BC Association for Behaviour Analysis
BC Association for Child Development and Intervention (BCACDI) and their 41 member agencies
BC Blind Sports and Recreation Association
BC Centre for Ability
BC CEO Network
BC Complex Kids Society
BC Family Hearing Resource Society
BC Disability Collaborative

BCEd Access Society
BC Federation of Parent Advisory Councils
BC Prader-Willi Syndrome Association
BC Pediatric Society
Blind Beginnings Society
Burnaby Association for Community Inclusion
Canadian Association of Occupational Therapists – BC chapter
Canadian Deafblind Association – BC Chapter
Canucks Autism Network
Cerebral Palsy Association of BC
Children's Autism Federation of BC
Children's Hearing and Speech Centre
Deaf Children's Society of BC
Disability Alliance BC
Down Syndrome Resource Foundation
Down Syndrome Society of BC
Dyslexia BC
Families Supporting Regular Equitable Authentic Lives (REA-L)
Family Network for Deaf Children
Family Support Institute of BC
Federation of Community Social Services of BC
First Call Child & Youth Advocacy Coalition
First Nations Leadership Council c/o the Union of British Columbia Indian Chiefs
Inclusion BC
Inspire Kids – FASD Society of BC
Kitimat Child Development Centre
Learning Disabilities Association Fraser South Chapter
Learning Disabilities Society
Northwest Child Development Centre
Pacific Autism Family Network
Physiotherapy Association of BC
Reach Child and Youth Development Society
Speech & Hearing BC
Spina Bifida Hydrocephalus Association of BC
Terrace Child Development Centre Society
Tsleil Waututh Nation
North Coast Community Services – Building Blocks Family Connection Centre
Variety – The Children's Charity of BC

Message from the Representative

In July 2024, the Office of the Representative for Children and Youth (RCY) released *Don't Look Away - How one boy's story has the power to shift a system of care for children and youth*. This report presented findings from an extensive sacred story investigation of a young boy's death, and illuminated the underlying systemic issues that are persistently getting in the way of child well-being. The report calls for an "all-in" approach to achieve both specific and larger transformative changes that will ensure that our young people are safe, connected and thriving.

While *Don't Look Away* did not specifically focus on the experiences of children and youth with disabilities and their families, the young boy at the heart of this sacred story investigation had complex medical and developmental needs. *Don't Look Away* highlighted the ongoing and overwhelming struggles that so many families caring for young people with disabilities experience when trying to navigate the tangled web of government services with little support and limited resources. Struggles such as accessing respite, appropriate school inclusion and support, eligibility and timely access to supports and therapies were some of the struggles highlighted and have



been overwhelmingly affirmed by the thousands of families who have generously shared their experiences with us. Their message is clear – they are beyond their breaking point and they cannot accept the current service delivery model for young people with disabilities any longer.

Since its inception in 2007, my Office has been shining a light on the needs of children and youth with disabilities, repeatedly calling on successive governments to address the systemic barriers these young people and their families face. Over the years, we have released numerous reports with clear recommendations and calls to action aimed at improving their quality of life. In 2018, early in my first term as the Representative, I released *Alone and Afraid* and recommended that government

undertake a comprehensive assessment of the needs of children and youth with disabilities in B.C. and investigate the capacity of the current system to meet those needs. In *Excluded* (2021), we highlighted the experiences of children and youth with Fetal Alcohol Spectrum Disorder (FASD) in B.C. and provided compelling evidence that young people with FASD are dramatically underserved. During the COVID-19 pandemic, *Left Out* (2020) documented the immense struggles that families faced in accessing disability-related services during and even before the pandemic. The follow-up report, *Still Left Out* (2023), revealed that these challenges persisted after the pandemic, leaving families still without the critical supports and services they need. Finally, in 2023, in collaboration with the Children's Health Policy Centre at Simon Fraser University, we released *Toward Inclusion* (2023), which emphasized the urgent and significant need for increased mental health supports for children and youth with disabilities.

The common thread throughout these reports is clear: children and youth with disabilities and their families are not receiving the supports they need to thrive. We continue to monitor progress on the past recommendations made in these reports, and while investments and efforts have been made, needs have continued to

grow. Overall, progress on the immediate and long term actions called for within these reports has been slow.

Government endeavoured to address many of the concerns through increased investments and a new framework for Children and Youth with Support Needs, within the Ministry of Children and Family Development. However, the proposed framework was strongly criticized by First Nations leaders and many disability organizations and families. In November 2022, Premier Eby announced a reset of the existing system of services for children and youth with disabilities and their families. This reset included an extensive community engagement process, led by community-based disability organizations and a commitment to thorough consultation with First Nations and Métis organizations and leadership. Over the past two years, we have gratefully walked alongside the disability community – with families, with children and youth with disabilities, and with dozens of dedicated disability advocacy organizations and service providers. Together their collective voices, insights, and lived and living experiences have deepened government's knowledge, and our own.

The engagement phase of the reset was recently completed and we now call on government to take the knowledge gained and continue to work collaboratively with the community during the next crucial phase, while weaving this work into the broader systemic changes called for in *Don't Look Away*.

While at first glance, it might seem that our recommendations and calls to action in our disability-focused reports over the past six years are distinct from the collective responsibilities and calls to action articulated in *Don't Look Away*, however it has become clear to us that they are deeply intertwined. The “North Star” of child well-being set out in *Don't Look Away* is highly relevant to children and youth with disabilities. This includes the importance of supporting families, working across ministries and sectors to meet the unique needs of young people with disabilities, being accountable to young people for positive life outcomes and being accountable for ensuring that supports and resources are effective.

As we continue to work collectively to move towards the “North Star” of child well-being, I am calling on government to situate its work strengthening services and supports for young people with disabilities within a collective cross-ministry responsibility to develop a Child Well-Being Action Plan. Strengthening services and supports for young people with disabilities is not just the

work of one ministry – it requires a collective approach across ministries to ensure we are truly making the progress that is so critically needed.

The recently released mandate letters for the Minister of Health and Minister of Children and Family Development, that call for the two ministries to work together “and with Indigenous peoples, key stakeholders and people with lived experience, to realign and improve services for children and youth with support and mental health needs,” is a clear recognition of the collaborative approach that is called for in these times.

I look forward, and more importantly, our young people and their families, look forward to a bold all-of-government shift toward child well-being. The proposed and recommended immediate and longer term transformational actions will make a positive difference in the lives of many young people and their families. Without this, the sacred lives and futures of children and youth with disabilities will continue to be at risk. We know better and I am confident that we can do better.



Dr. Jennifer Charlesworth
Representative for Children and Youth

We know that over the past five years, children and youth with disabilities are overrepresented in government care with an average of 41 percent of all children in the care of the government identified as children and youth with disabilities and/or with support needs.



Underfunded and Disconnected Systems

Children and youth with disabilities have been the focus of a number of RCY reports over the past 18 years. RCY's recent report, *Don't Look Away*, (DLA) that resulted from a sacred story investigation and systemic review, highlights the experiences of a number of children whose lives were negatively impacted by a system that struggled to provide the comprehensive, high quality, wraparound care and support needed for their well-being. The young people in that report and the countless others whose stories we encounter through our day-to-day advocacy work and our work reviewing and investigating serious injuries of young people,

demonstrate remarkable resilience and determination despite ongoing challenges within a system that remains underfunded, fragmented, difficult to access, and challenging to navigate.

Many families struggle to afford specialized medical supplies, find transportation for multiple appointments, access reliable respite care, secure suitable and safe housing, and access therapies, mental health and other essential supports. Instead of a cohesive system of care, families often encounter uncoordinated services that too often look away or only address discrete issues or needs without understanding the child and family context and their interconnected challenges. In fact, *Don't Look Away* found over 40 instances within the sacred story where the opportunity for the system to reach in or respond effectively to the child's complex health needs were missed, contributing to the child's basic rights being denied.

The experiences of these children are far from unique and the challenges their families face become even greater when living with additional complexity. This is also true for the families who are raising the over 120,000 children and youth with disabilities in B.C.¹ So many of these families struggle to navigate across multiple government systems to get the supports their children need to thrive.

“It is the system, not my child, that is the cause of our family's stress and struggles.”

– Parent, RCY Engagement Session, 2024

The Impact of an Underfunded System

Unsupported families continue to tell RCY that the lack of adequate services means they are being pushed to their mental, financial, emotional, physical and spiritual limits which impact their ability to care for their children. For example,

a May 2024 RCY interview with the mother of five children, three of whom have complex support needs, exemplifies the struggle that families still face in an under-resourced, underfunded, and fragmented system of care.

“From my own experience. You get to the point where maybe your child hasn’t slept for four days and you’re physically exhausted. You haven’t been able to go to work, so are you worried about finances. Your child is physically assaulting you. They’re claiming that they’re going to harm themselves. They may not have the developmental understanding even of what that is. And then you get to a really dark place yourself and go, I can’t do this anymore, right? And I can’t do this anymore can mean, I need to surrender my child. Which is heartbreaking.



Like that’s just an awful feeling or, to the other extreme, where nobody else can take care of my child and I can’t do this anymore so I’m going to harm myself and my child because that is the only option and the only light I can see going forward.

We are failing as a province if that is how people are feeling. Honestly, and I was very close to that myself this Fall where it was just exhausting, and my kids were struggling.

Everything was hard and it got to the point where I was starting to have these thoughts. And I mean, I went to a doctor, and I got support. But for so many people, what if they don’t? Right? Right.”

– Parent, RCY Engagement Session, 2024



Disability Voices Must Be at the Table

Families have told RCY repeatedly that their child is not the cause of their struggle – it is the disconnected and underfunded system that holds them down instead of lifting them up. Children and youth with disabilities, like all children, have the right to thrive.² Over the years, RCY has engaged with thousands of families through in-person engagement sessions, virtual family gatherings, connections with community partners and service providers, and most recently through an RCY survey conducted in the Fall of 2023 that was completed by more than 1,160 families across the province.³ What we continue to hear from the disability community directly aligns with key recommendations that RCY has made for years across five key reports including the most recent report stemming from an investigation into the tragic death of a young boy which included a broad systemic review. The *Don't Look Away* report identified key opportunities to transform the system of supports and services for children and youth and their families – including for young people with disabilities – from one that is reactive and focused on protection and risk, to one that is proactive, preventive and focused on well-being.

Through this spotlight, RCY, alongside members of the disability community, is sending a clear message – the time to act for children and youth with disabilities is now.⁴

Both immediate action and long-term transformational change must be a priority and as we move our system to one that is truly focusing on child well-being the voices and rights of children and youth with disabilities and their families must be actively at the table.

Disability is Not a Bad Word

In this spotlight, we refer to children and youth with developmental or complex medical conditions as “children and youth with disabilities,” not as “children and youth with support needs” (CYSN). In B.C., the term CYSN is tied to a specific service delivery system within the Ministry for Children and Family Development (MCFD) – a system where many of the services require a specific diagnosis to access.⁵ Children and youth with disabilities and their families clearly require services and supports from a multitude of sectors and ministries, not just MCFD. Therefore, we use children and youth with disabilities to describe all children and youth under the age of 19 with a disability or suspected disability who require services across sectors and ministries (e.g., MCFD, Health, Education and Child

Care, Social Development and Poverty Reduction, Housing, etc.) regardless of diagnosis.⁶

The term children and youth with disabilities also better reflects what we are hearing from the broader disability community, which emphasizes that being born with a disability is a part of the human condition. In Canada, 27 percent of people have a disability and as we age, we are all more likely to experience some form of disability.⁷ Disability is not a “bad” word or condition; for many it is an inherent part of who they are. A person is not only disabled by what they cannot do but also, and sometimes more greatly, by the societal barriers placed before them. For thousands of children and youth with disabilities in our province, these barriers start early.

The Numbers

RCY’s analysis (see Appendix A) estimates that between 55,000 and 83,000 children and youth with disabilities and their families are not receiving the publicly funded supports they need from Ministries like Children and Family Development, Health, Education and Child Care, Housing, and others.


While not all the 55,000 to 83,000 children and youth with disabilities

may need the current suite of MCFD CYSN services, many may benefit from services delivered or funded by other Ministries such as Health or Education and Child Care. However, without accurate data across service sectors, the only thing we do know for certain is that far too many children and youth with disabilities have gone unserved or underserved for far too long.

Why Does This Matter?

The impact on children and youth with disabilities who are continually left out of and/or denied their right to access services in their childhood years is well-documented. Research consistently demonstrates that, without timely intervention, a child's ability to thrive and develop life-changing skills is seriously diminished.⁸

In addition, not providing timely services in childhood can lead to greater costs for families and society in the long-term. The 2007 Senate report *Pay Now or Pay Later* highlighted the economic impact of failing to provide early intervention services to children with disabilities, in particular those on the autism spectrum.⁹ More recently, [a study by the Canadian Institute for Work and Health](#) examined the economic benefits of becoming a fully accessible and inclusive society.¹⁰ One of the domains they used to define the conceptual framework for inclusion and accessibility was a society that helps families who have children with disabilities with everyday tasks and adequately covers costs such as prescription and nonprescription drugs, specialized equipment, social services, and transportation. Overall, they found that “the economic impact of Canada becoming a fully accessible and inclusive society in all . . . domains added up to a benefit of about \$337.7 billion a year” or 17.6 percent of the gross domestic product.¹¹



In the interest of equity, I would really like to see support given how it's needed and when it's needed..... and no waiting please. It feels like everything we do is reactionary and then ends up costing the system actually ironically more than if we just provided what was needed at the time that it was needed.

– Parent, RCY Survey



How We Got Here

With the release of *Don't Look Away* came a commitment by government for “fundamental change” – and an historic acceptance of all RCY’s recommendations.

“It is time for a fundamental change that focuses more on providing families with increased supports so that children and youth have what they need to be safe, healthy, and thriving.”

– Minister Lore, MCFD, upon the release of “*Don't Look Away*” July 16, 2024

The question is no longer whether change should happen, but rather how it can be achieved both in the short-term and through long-term service transformation. Furthermore, how can this system transformation ensure that the unique needs of children and youth with disabilities are fully addressed?

RCY has been shining a light on the rights of children and youth with disabilities since the office was created in 2007. A total of 12 reports have repeatedly highlighted three key themes related to inadequate services and supports for children and youth with disabilities that were reiterated in *Don't Look Away*.¹²

The three key themes we need to achieve are:

1. Effective cross-ministerial/ cross sectoral collaboration and an integrated approach to serving children and youth with disabilities and their families.
2. A funded and equitable service delivery system that is easy to navigate and is based on the needs of all children and youth with disabilities and their families.
3. An effective and comprehensive data collection system across government to determine how many children and youth with disabilities need to be served and how best to serve them.

Government, past and present is well-aware of these issues and for over 20 years, governments of all stripes have recognized the gaps and have made promises to build a better system of support for children and youth with disabilities.

In 2002, Linda Reid, Minister of State for Early Childhood Development stated, “This government promised to increase emphasis on early childhood intervention programs for families with special needs children, and we have.”¹³ In 2003, the Ministry of Human Resources stated, “Persons with disabilities – particularly children with disabilities – are one of the highest priorities of the government of British Columbia.”¹⁴ Fast forward to 2023 where Mitzi Dean, Minister

of Children and Family Development stated, “Too many children aren’t getting the services they need today, and we are committed to building an effective system of supports.”¹⁵

Despite government’s acknowledgment of the gaps in the system, over 50 specific recommendations from RCY across 12 reports over 18 years, and persistent calls for action from the disability community, the majority of children and youth with disabilities still do not receive the full range of services they require. Only 32 percent of families surveyed by RCY in late 2023 agreed that the services they receive meet their children’s needs. As we welcome 2025, we acknowledge the efforts made to change the system for children and youth with disabilities, but we also face the hard reality that we continue to experience a system that is underfunded, disconnected, and inequitable, leaving tens of thousands of children with disabilities without services every year.

Take, for instance, government’s response to RCY’s 2018 report *Alone and Afraid: Lessons Learned from the Ordeal of a Child with Special Needs and his Family*, which detailed the story of a 12-year-old autistic non-speaking boy who was removed from his mother’s care in 2016. “Charlie” was found alone in his home by the police.¹⁶ RCY discovered that he had endured years of poverty, neglect, and malnutrition. He was disconnected from social, education and health systems because his mother was left to navigate a fragmented and complex web of services with little support. She was afraid to reach out to ask for support for

her own mental health and substance abuse conditions and the systems of care did not actively reach in to support Charlie and his mom to thrive.

The B.C. government was quick to respond to *Alone and Afraid* and on December 10, 2018, Katrine Conroy, then Minister of Children and Family Development, issued the following statement on behalf of government:

“We accept the intent of each and every one of the representative’s recommendations, and there’s much more work we will do to address the challenges they highlight. As the report documents, families seeking support for children with special needs face a fragmented system. Our government is developing a special needs (CYSN) services framework to guide the delivery of these services to better meet the specific needs of children and their families. This framework will address some of the key challenges outlined in this report. Early on, Charlie’s mother needed respite care but couldn’t get it because of policy and service barriers. That will change. We acknowledge that families are asking for more resources and respite services and that our policies need to be more flexible to respond to the unique circumstance of each child and family.”

– Minister Katrine Conroy (MCFD) ¹⁷

It is now over six years since *Alone and Afraid* was published, and government actions in the form of (1) a comprehensive assessment to understand the actual need for disability services across B.C. and the capacity of the current system to meet those needs; (2) more resources and more services that support both children and their families; and (3) an integrated cross-ministry service delivery model to make true systemic changes to serve all children and youth with disabilities across the province, are minimal and the impact on families is almost non-existent. In fact, a four-year review by RCY on the progress of the *Alone and Afraid* recommendations, released in 2024, found little movement by government, with actions on some of the recommendations even deteriorating over time.¹⁸

Unfortunately, this means that tragedies keep happening. Government's responses in the past are often reactive or 'on the edge of the system solutions' that do not substantively address the systemic barriers compromising the rights of children and youth with disabilities in this province.

As examples, let's examine the government's responses to two recent RCY reports (*Alone and Afraid*, 2018 and *Excluded*, 2019). In both cases, government responded with much-needed increases to respite funding for families. Respite involves the temporary care of an individual with a disability for the

purpose of providing relief to the parent or primary caregiver. In 2019, government announced a \$6.3M boost to the province's respite program to fund an additional 1,300 families and to increase the base annual funding that each family receives from \$2,800 to \$3,080 – a change that government announced as “the first increase in respite funding since 1989” – 30 years.¹⁹ Budget 2023, followed, with a further rate increase from \$3,080 to \$4,135 per year for all respite services (i.e., not just for children and youth with support needs).²⁰

RCY analyzed government respite expenditures from 2019 to 2024 to assess the impact of the \$6.3 million boost in respite funding in 2019 and the overall respite rate increase in Budget 2023 (from \$3,080/yr to \$4,135/yr for Direct Funded Respite and from \$2,800/yr to \$4,135/year for Agency Coordinated Respite – ACR).²¹ We were pleased to find that funding for the additional 1,300 families supported by these increases has been maintained over the past five years and that an additional 550 families were able to access ACR. However, we also observed that since the 2020 increase, growth in respite funding has flat-lined for three years (2021 to 2023) and is now trending downward, resulting in a negative growth rate of 2 percent.

These findings align with what we have heard directly from families across the province: access to respite care, an essential service that helps families stay healthy and together, is not keeping pace with demand. In the

RCY survey, respite was identified as the third highest service need, yet only 28% of families reported receiving it. Here is some of what families told us:

“Why can’t respite funding just be something that everyone receives? I wish MCFD would improve the horrible process for waiting for all these services.”

“There needs to be added funding by the government for families to receive respite. Most families are clinging to what they have and it’s not nearly enough. Families desperately need this. Why not be proactive and offer this to families (rather) than have families collapse because they are burnt out.”

“I had respite funding for all 4 kids and then lost it for 3 of them which was a really hard blow for the kids and my mental health. I feel as a single parent it’s hard to meet the daily needs of 4 special needs kids and my social worker doesn’t see my struggles. Raising 4 special needs kids not getting a moment to myself and having to always be on guard day and night.”

RCY also heard from Children and Youth with Support Needs (CYSN) workers in a 2024 Workforce survey.²² Many of the respondents commented that respite funding is insufficient to meet the needs of the families that they are so desperately trying to support. Here are just a few of their comments:

“There has been no increase in basic services for families, such as direct funded respite.”

“The respite list is extremely long with most parents never having a chance to get respite.”

“NEW CYSN policies are limiting families access to RESPITE funds by greatly reducing the number of eligible families.”

“Waitlists for respite, positive behaviour support, social groups, and 1:1 child youth care workers are in such high demand that many families may not receive these programs before they age out of our services.”

Next we examined the response to the RCY report [*Excluded: Increasing Understanding, Support and Inclusion for Children with FASD and their Families \(2021\)*](#). In 2022, one year after the report documented the fact that families of children and youth with Fetal Alcohol Spectrum Disorder (FASD) receive little to no respite at all, government provided additional funding for respite care specifically for these families. In that instance, they awarded a \$2.76M, 2-year, “one-time funding” grant to the Vancouver Foundation to administer the distribution of respite funding to families of children with FASD.²³

Not only did the one-time funding fail to address the ongoing systemic need for respite services for children with FASD and their families, accessing these limited funds was also problematic. Families were required to apply, but the number of applicants far exceeded the available funding.

Consequently, a province-wide lottery system was implemented to determine which families would receive the respite support.

This forced families to essentially compete against one another for funding. For those who “won” the lottery, the experience often led to feelings of guilt, knowing others were left without support, or a sense that they must remain perpetually grateful for being chosen.

“It would be nice if we didn’t have to put our names in a lottery hoping we will get support money and having our hopes dashed because we didn’t qualify [for the lottery]. The government saying that there is all this money coming out for people, but you have to qualify. I didn’t qualify for any of these extra funds. It makes it very hard to say to your child, I’m sorry but we didn’t get any money because we [didn’t win the lottery]. It’s really hard for a parent, especially single parents.”

– Parent, RCY Survey

“Did not know about lottery system to get respite support for FASD, and even if we would have been informed about it, would be very conflicted about it, as we would be competing for a chance for supports and the way of acquiring these much needed supports is very demeaning and not equitable. (Very traumatizing way of potentially receiving supports after going through a system that has never provided these supports even with proper assessments/diagnosis).”

– Parent, RCY Survey

RCY notes that government recently announced a 60% budget increase to agency-coordinated respite in Budget 2023. This is encouraging, although the impact of this increase is not yet known.



Having To Do More with Less

In B.C., Child Development Centres (CDCs) provide many of the community-based services to children and youth with disabilities, including essential therapies, Infant Development and/or Supported Child Development programs, and so forth.²⁴ RCY has heard from leaders across the province that the CDC system has been historically under-resourced, inequitable, and underfunded for years. Although the funding they receive has increased somewhat year over year, it has not kept up with demand, so many CDCs are having to do more with less and all undertake

extensive fundraising in an effort to meet at least some of the needs of the children and families coming to them for help.

To illustrate this, RCY examined the Early Intervention Therapies (EIT) contracts from 2006 and 2023 from two CDCs – one in a northern rural community and one in an urban location.²⁵ We found that both CDCs are serving more children in 2023 than they did in 2006 but with less funding per child, which inevitably impacts the quality of service that each child and family can receive.

CDC Community	2006 Unique Children Served	2006 EIT Cost per Child per Year	2023 Unique Children Served	2023 EIT Cost per Child per Year	Cost per child decrease from 2006 to 2023
Northern B.C.	154	\$3,178	371	\$1,842	42%
Urban Centre B.C.	1,029	\$1,549	1,596	\$1,302	16%

The data aligns with what we are hearing from families who access government funding and what we are hearing from community service providers across the province – funding is not keeping pace with the increase in service demand.

“Autism Funding has failed to keep up with the increased cost of living and living wages over the past 20 years, and families have to pay more now for less services as the funding has not increased to keep up with the times.”

– Parent, RCY Survey

“I don't know that we've ever had a fair crack at actually demonstrating our value because we're not adequately funded.”

– CDC Coastal Community Service Provider

“You know, you look at the eco density in (our community), what was a plaza is now condos or you know, what was a house is now a tower and so you know thankfully there has been that investment. But it almost just seems like there's just been this unfair disadvantage over the years where there's feedback about how (our) programs aren't working, but they weren't funded properly to work, according to what they needed to be doing to support families.”

– CDC Coastal Community Service Provider

“The funding doesn't necessarily follow with the need, and over many, many years it has stayed the same while in many places populations have been increasing. And we are feeling that now.”

– CDC Interior Community Service Provider

Where We Are

In October 2021, B.C.'s Ministry of Children and Family Development (MCFD) announced a plan to establish a new service system (called the Children and Youth with Support Needs (CYSN) Framework), through the implementation of 40-45 one-stop "family connection hubs" – now known as Family Connections Centres (FCCs) – and proposed the elimination of individualized funding for children diagnosed with autism to help fund a shift to the new FCC service model.^{26,27} The plan was aligned with previous reports and recommendations by RCY and the Select Standing Committee on Children and Youth (SSCCY). It was also informed by a community consultation process conducted in 2018/19; a review of academic literature; and input from researchers at CanChild, an international organization focused on improving the lives of children and youth with disabilities and their families. The stated intention of the new framework was to address many of the service gaps and inequities that are inherent in the current system.

However, MCFD's 2021 announcement received mixed reviews. While many families who had not been receiving services were hopeful, significant concerns were expressed by Indigenous leaders and community representatives, by parents/ caregivers of autistic children receiving individualized funding – both as individuals and as members of disability advocacy groups – and by numerous community and

professional organizations regarding (a) the process by which MCFD developed the new framework and (b) the types, quality, and quantity of services that were to be available through the framework. In particular, the Union of BC Indian Chiefs (UBCIC) rejected the new framework and, in a May 16, 2022 news release, stated that the government was "steamrolling Indigenous families, and all families of children with disabilities by trying to impose a centralized, MCFD-controlled system of services for children with disabilities without proper consultation, co-operation, or consent. British Columbia's reckless and harmful policy shift has been developed in violation of the requirement of the *Declaration on the Rights of Indigenous Peoples Act*."²⁸

There was also widespread concern about the lack of consultation with key disability groups regarding potential solutions to deficiencies in the current system and great concern with the proposal to eliminate individualized funding for children with autism.

In response to these concerns, in November 2022, Premier Eby announced:

1. Maintenance of individualized funding for children and youth with an autism diagnosis;
2. A pause in the roll-out of the plan to establish a network of FCCs, except for four pilot sites in Central Okanagan/Kelowna, Haida Gwaii/ Prince Rupert, Terrace/Kitimat, and Bulkley Valley/Stikine;

3. Implementation of an engagement process co-designed by First Nations leadership and leaders from the disability community, in partnership with government; and
4. New investments in the interim, during development of a system to support children with disabilities and support needs that are currently underserved.

The “pause” announced in 2022 has now been over two years in length, and although four pilot FCCs are operational, the reality is that these sites only serve six percent of the population of children and youth with disabilities in B.C.²⁹ This leaves 94 percent of children and youth with disabilities and their families across the province dependent on the existing under-resourced CYSN system. Even for the six percent of the children and youth with disabilities population who reside within one of the four pilot FCC sites, there are still gaps. Some service delivery changes are showing encouraging early signs of success and access to services is becoming easier for some families; while other families report that they are still not receiving the services they need. In the 2023 RCY survey, one caregiver expressed their frustration about this process, writing:

“It is great that a pause happened. However, I fear it is an example of government just kicking the problem down the road. There have been multiple reports from the RCY office, input from families and service providers, and very little changes.” The most recent engagement process started in March 2023 with the final report not expected until spring 2025.³⁰

2025 marks seven years since the initial 2018 consultations started on the CYSN service framework.³¹ That is seven crucial years of lost opportunities for children and their families to receive the early interventions, therapy supports, respite, and other wraparound services that could have changed their developmental and well-being outcomes.

As we wait for the final report in 2025, it should be noted that Budget 2023 did bring forward welcomed announcements to address some of the immediate inequities across the province. The 2023 Budget announced new investments of \$34.5 million over three years for services to children and youth with support needs that are currently underserved, including children and youth with FASD and other neuro-cognitive developmental disabilities:³²

- Providing funding for an additional 90 foundational program therapists across the province for programs such as infant development, early intervention, and school-aged therapies through investment in Child Development Centres or similar organizations in every community in the province;
- Doubling the budget for Fetal Alcohol Spectrum Disorder Key Worker program, which will allow support for approximately 2,500 additional families of children and youth with FASD;
- A 60% budget increase to agency-coordinated respite, which will enable the program to expand to all regions of the province; and

- Adding an additional 175% above the province's current investment in School Aged Extended Therapy by doubling hourly reimbursement rates from \$80/hr to \$160/hr and increasing the annual maximum reimbursement to \$5,760 per year.

RCY has examined the "funding for an additional 90 foundational program therapists across the province." We found that in the fiscal year 2023/24 government provided approximately \$4.1M of the \$25.8M in new funding announced for 90 foundational therapists and therapy assistants.

Encouragingly, the Office is hearing that as this funding is rolled out, it is beginning to make a difference, demonstrating that increased funding for therapies can significantly improve access to services and positively impact the lives of children and youth with disabilities. For example, two community service providers shared that, despite challenges with recruitment, they were able to fill all newly funded positions, and these positions are now having a tangible positive impact on the lives of children and families they serve.



"As a result of this additional FTEs, our families now have access to services with reduced wait times and better caseload distributions among staff."

– Service Provider

"We have been able to increase the numbers of families served as a result of staffing increases to Foundational Programs. Therapy Assistant is further increasing capacity cost effectively for groups and 1:1 and we are able to recruit them easily."

– Service Provider

Next, we examined the 2023 commitment to "double the budget for FASD Key Worker program, which will allow support for approximately 2,500 additional families of children and youth with FASD." Here is what we found.

We analyzed the CYSN financials to find out what "doubling the budget" entails. The expenditure budget for the FASD Key Worker program just prior to 2023 was approximately \$6.8M. Therefore,

we would expect this funding to double to \$13.6M by the end of fiscal 2025. So far, we have seen only a small increase in expenditure (excluding collective agreement increases) and it is too early to assess the impact but we are confident that this funding commitment, if realized, will make a meaningful difference in the lives of thousands of children and youth with FASD across the province.



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Calls to Action

In *Don't Look Away*, RCY called on government to address five key Collective Responsibilities to fundamentally transform the systems of care that are intended to support children, youth and families. This spotlight report reminds government that any transformation for child well-being must include and consider the needs of children and youth with disabilities and their families.

Under each Collective Responsibility, RCY makes several recommendations both for long-term collective action across ministries and health authorities and urgent action specific to MCFD, Public Safety and Solicitor General and Ministry of Finance. Three of these Collective Responsibilities relate directly to the systemic issues highlighted in this spotlight that have faced young people with disabilities for nearly two decades.



Collective Responsibility: Focus on Child Well-Being

In *Don't Look Away*, the Representative recommends that the Government of British Columbia establish a Child Well-Being Strategy and Action Plan to guide a coordinated whole-of-government approach that will improve the well-being and outcomes for all children, with particular attention to those children and families experiencing the greatest inequities in the province of B.C.

Children and Youth with Disabilities Call to Action:

Establish effective cross-government collaboration to address the inequities experienced by all children and youth with disabilities and their families.

When we look at *Don't Look Away*, it is too easy to see that many children did not neatly fit into one service delivery “box.” Most required services across multiple systems, including health, social services, education, housing, and income support. Importantly, they need proactive help navigating between these systems. But to take it one step further to an ideal state, children and youth need an integrated system that sees them as a “whole” child and responds to those needs accordingly.

For children and youth with disabilities, numerous service systems are almost always involved because a child and family rarely have “one” issue. For example, the RCY Survey found that 41 percent of children and youth with disabilities also had a co-occurring mental health condition. Many of the children and families in the sacred stories we highlighted in DLA and those that continue to become known to us through the hundreds of reports of injuries and deaths we receive each month also experience an intersectionality of inequities. As an example, a First Nations child with a disability, whose family and community has experienced colonial violence and harms over generations, may also be experiencing family poverty, housing and food insecurity, family

mental health and substance misuse challenges. Unfortunately, in B.C., the more “complex” a child is, and the more systems involved, the less likely it is that the systems will actively wrap around the child and family in a coordinated manner. Instead, much of the burden to find out what is available and how to access services is placed on the family.³³ In fact, the RCY survey found that 81 percent of families struggle to navigate the broad disability service system.

For years, families have been left to navigate between health and social service sectors on their own. The sad reality is that for many families this is too much, and they are left feeling overwhelmed and guilty for not “keeping up.” This was a common theme in the feedback from the RCY survey:

“The burden is placed squarely on the shoulders of the parents to navigate this horrific system while we are under slept, overwhelmed, stressed, etc. The bureaucracy and red tape and confusion regarding programs would be difficult to manage at the best of times let alone while we are trying to manage what is often a chaotic home life. Case in point, I have barely had time to respond to this survey. I could go on, you get the picture.”
– RCY Survey Respondent



“While our family now feels equipped to be able to do some of this work in our home and find those resources and do that work, they should be supporting us to do that. But they’re not. And so that’s the problem.”

– Parent, RCY Survey

Impossible Decisions

RCY has heard hundreds of heartbreaking stories from families who are stretched to the breaking point. While many children and youth with disabilities receive services through MCFD’s Children and Youth with Support Needs (CYSN) system, the RCY survey found that 44 percent of families reported that their child was NOT eligible for services in the current CYSN system.

In some cases, families told us that due to the lack of services, they are forced to make impossible decisions. The RCY survey found that 14 percent of families have considered placing their child in care for the sole purpose of getting services that would not be funded if their child stayed in their own home. This percentage rose to 16.4 percent for families with Indigenous children. The survey also revealed that for families whose children were in the care of the government, 20 percent said they made that decision because it was the only way they could secure the necessary support for their child.

Over the past five years, children and youth with disabilities represent 41 percent of all children in care – an over-representation.³⁴ Sadly, placing a child or youth with a disability in care does not guarantee more services and better outcomes.

“It is ludicrous that if we place our children in a voluntary care model the caregivers would get funding but parents wishing to continue supporting their own children are not supported in this way and unnecessarily pushed into poverty to care for their children. We chose to be parents and became caregivers also. Government funding should support families wishing to stay unified rather than incentivizing families to place their children in care because of financial strain. Most of us cannot work due to the needs related to our child’s disability. It is not something we could have planned for and cost of living is precariously high. This is unsustainable and terrible for our children and families.”

– Parent, RCY Survey

“My child was put in care to give her the services she needed. It was a cruel choice.”

– Parent, RCY Survey

“MCFD is a very dysfunctional system that does not support keeping complex children in the family. Instead they say only option is to put child in full time care.”

– Parent, RCY Survey

“I (wish I) would be given what I need to keep my son living with me at home and not be in a situation where I chose to put him in care so I could work, and he could have his needs met. Where he is now they are paid over \$7500 a month and have enough money to hire a nanny to help them. I was given a max of \$1200 a month. That is disgraceful.”

– Parent, RCY Survey

Addressing the Needs of the Whole Child and Family

Children and families do not live in silos, yet many of our service systems do. This disconnect leads to unnecessary barriers for families attempting to access services and supports that could make a meaningful difference in their lives. One critical area of need is mental health supports for both children and youth with disabilities, as well as their families.

In 2023, the RCY collaborated with the Children’s Health Policy Centre (CHPC) at Simon Fraser University to learn more about mental health services for children and youth with neurodevelopmental conditions which informed the RCY report, *[Toward Inclusion: The need to improve access to mental health services for children and youth with neurodevelopmental conditions](#)*. The CHPC found that the five most common childhood mental disorders overall — anxiety, ADHD, oppositional defiant and conduct disorders, and depression — were much more prevalent for children with neurodevelopmental conditions as compared to the general population.³⁵

Another recent study in 2024 supports their findings and revealed that children with disabilities are more likely to experience co-existing mental health issues (e.g., anxiety, depression) compared to their typically developing peers.³⁶ The authors noted that approximately 70 percent of mental health challenges emerge during childhood, with lifelong consequences extending into adulthood. The RCY survey also echoed the co-occurrence of mental health and neurodevelopmental conditions, finding that 41 percent of all children and youth identified through the survey had a mental health condition (either co-existing or stand-alone). Among Indigenous children and youth, the figure was even higher at 63 percent.

Mental health challenges were also not just experienced by the child or youth, families responding to the RCY survey reported being exhausted, with the stress of navigating a fractured system directly impacting on their own mental health and that of other family members.



“My mental health has deteriorated, my partner has had to quit her job, we are four mouths on one income in one of the most expensive places to live in North America. This is not sustainable. We want our child’s medical needs taken care of so we can be parents. We are not nurses.”

– Parent, RCY Survey

“Emotionally, parenting children with support needs is not for the faint of heart. Mine has been broken for my child too many times to count. I have had to sacrifice so much and fight for everything my child needs and I’m exhausted. We are a two-parent household, and my husband has been on an 8 month medical leave for stress from work and burnout and if that was an option for me, I’d gladly partake (maybe far away from everyone). My mental health is the pits and in times of crisis when you do have a child with violent behaviors, the RCMP is your only option.”

– Parent, RCY Survey

It is clear there is an urgent need for mental health services for both children and youth with disabilities and their caregivers. Families and RCY are once again calling out for these services.

The 2023 RCY report *Toward Inclusion* explored this issue in depth. The report emphasized that best practices involve services that take a whole-child approach—services that seamlessly wrap around both the child and the entire family.

Failure to include children and youth with mental health (CYMH) services within the overall CYSN or disability framework not only impacts children and families but also compromises the ability of existing service providers to fulfill their roles. For example, the RCY workforce survey revealed that 64% of CYSN workers reported that they did not have training to effectively address the unique needs and circumstances of children and youth with complex

needs.³⁷ CYSN workers also lack access to professional mental health supports to assist them in planning for the chronic mental health needs of children and their families. Both the lack of resources and training to identify evidence-based mental health supports contributes to increased stress for the child, the family, and the CYSN worker.

“Stress plays a large role in daily work life unfortunately. When I’m having work-mares, I know I am struggling. The high stress and lack of resources very much impacts my personal mental health and job satisfaction.”

– CYSN Worker, RCY Workforce Survey

“The family community support resources are sorely lacking in my geographical area. Wait lists are ridiculously long, and there is nowhere near enough support to go around to even a third of the people I work with. Never mind all of them.”

– CYSN Worker, RCY Workforce Survey

As the *Toward Inclusion* report states: “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” (p. 4).

This is Not New

As demonstrated in the *Toward Inclusion* call to break down barriers to mental health services for children and youth with disabilities and their families, the call for ministries to work in collaboration with sectoral partners and develop an integrated/one-government service delivery framework for children and youth with disabilities is not new. This recommendation or theme has emerged in ten previous RCY reports dating back to 2010.³⁸

We have also known for years that when systems do not coordinate and work together, there is a compounding negative impact on the well-being of the child and their family. Let's take for example how services, or lack thereof, in one system impacts the child and family in another system, using the interconnection between the Ministries of Health (MoH), Child and Family Development (CFD), and Education and Child Care (ECC).

- Currently, thousands of children and youth are not being diagnosed in a timely manner through the MoH. The current wait time for an assessment through [BC Autism Assessment Network \(BCAAN\)](#) is as long as 27 months depending upon where the child and family lives in B.C.; as of March 31, 2024, 10,828 children under the age of 19 were on the waitlist.³⁹

The current wait times for an assessment through the [Complex Developmental Behavior Conditions \(CDBC\) Network](#) for children and youth who have difficulties in multiple areas of function are as long as 16 months; as of March 31, 2024, 969 children under the age of 19 were on that program's waitlist.⁴⁰

- The lack of a timely assessment means that many children are not diagnosed before they enter school. Therefore, they miss out on receiving essential early intervention services prior to school entry because many of the key services within the current MCFD CYSN system such as the At Home Program or Autism Funding require a diagnosis or an assessment of eligibility to access.⁴¹
- The absence of early intervention services before entering school often leaves many children unprepared. It also can delay their inclusive education designation, which could grant access to additional educational supports. This further burdens teachers, who are already stretched beyond reasonable capacity and unable to fully address these children's needs. A school based Speech-Language Pathologist (S-LP) revealed that they are now seeing far too many children entering the school system who have never been seen by a therapist and have now lost valuable developmental therapy time.

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“This in a town where a brilliant little boy who is 7.5 years old has never been seen by anyone and is now non-verbal (silent) – he will never speak. This child would be able to talk if he was helped sooner, and this is not the only case. I have never seen this degree of need in young vulnerable children anywhere. It’s distressing and makes me want to leave.”

– S-LP, RCY Engagement Session, 2023⁴²

- When more children enter the school system unprepared, schools are often unable to provide the services they need. Families have told RCY that, as a result, some of these children may be allowed to attend school only part-time, others are excluded for months, and still others are excluded altogether. The latest report on public school exclusions of children and youth with disabilities from BCEd Access reveals that there was a 173 percent increase in reported exclusions lasting over 4 months in 2022/23, compared to 2021/22.⁴³ In addition the BC Ombudsperson has recently announced that they are undertaking an investigation into school exclusion, which is an indication of the significant systemic concern.⁴⁴
- Once a child is excluded from school, it not only impacts their future educational and social development opportunities but also places additional pressure on families who must once more take on additional responsibilities and stressors to care for their children, while often not being eligible for supports provided by other systems.



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“The schools think community services is doing something. The silos are infuriating and inefficient. I’m at an edge. I know a lot of people are drowning. But also, what are we going to do? We can’t just keep drowning. I can hardly pull this off and I know people need more help than what I’m getting. I know there’s more desperation out there.”

– Parent, Vancouver Island, 2024

"Last year my son wasn't allowed at school for more than 2 hours a day. So, I had to go and pick him up. I drop both my kids off in the morning go back and pick him up 2 hours later. And I still had my daughter at home full time and for a lot of years my husband worked, you know. He went to work early, he went to work at 5:30 in the morning, came home at 2 and I worked 3 to 11, 5 days a week. Essentially, I was sleeping maybe 2 to 3 hours a night and then going to work. It's the burnout."

– Parent, RCY Engagement Session

"I don't think the general public knows all the exclusions and limitations imposed on families with children with support needs. Before my son started school, I was looking forward to that, thinking 'I'll have some experts to ask for advice on how to handle xyz' and it turned out to be quite the opposite."

– Parent, RCY Engagement Session

"We had to pull my daughter out of public school because there were very little supports for her. I spent all my time trying to explain to teachers, principals, staff, etc. what the needs were, fight for support and accommodations, and it was a disaster. Now my husband and I are trying to home-school, but we both also work full-time – and have to, in order to pay our rent in Vancouver. So we end up working early in the morning and late at night, to make sure we can still do our jobs adequately. This is placing major stress on our family life and our physical and mental health. We are cobbling together money to do a psych ed assessment privately (because the school won't fund it) and then we'll be paying out of pocket for any services we need."

– Parent, RCY Survey

Many caregivers also report having to adjust their employment status or not being able to work at all either because their children are excluded from school and/or because there is no accessible and appropriate childcare options, especially before and after school care for children

over the age of 12. Consequent impacts include financial, housing and food precarity, physical and mental health stressors on family members and loss of extended health benefits provided through work.



“I continue to not be able to work due to lack of access to childcare. Waitlists make it impossible to start working. I cannot leave my children with a casual babysitter, as their needs are too high.”

– Parent, RCY Survey

What we heard from families in the RCY Survey also supports the need for effective cross-government collaboration to address the well-being of the whole child and the whole family. Here is some of what we found:

- 38 percent of caregivers report needing mental health supports for themselves and/or members of their caregiving circle (e.g., relatives, siblings, and others living in the home);⁴⁵
- 64 percent of all caregivers have had to use their extended health benefits to fund services that support their own caregiving needs (e.g., mental health supports; family counselling; massage therapy; etc.) and 12 percent do not have these benefits;
- 79 percent of caregivers reported they either had to leave their job or reduce their hours of work to care for their child with a disability, or they had to increase their employment to pay for the services their child needs, pushing families into poverty and impacting caregivers’ future career development, mental health, and well-being;
- 83 percent of all caregivers reported that they had to use their own funds to pay for assessment, therapy, equipment, and transportation costs that are related directly to their child’s service and support needs;⁴⁶
 - ◆ 73 percent of caregivers spend between \$100 to \$1,000 each month on services and supports related to their child’s disability that are not covered through government funding;
 - ◆ 10 percent of caregivers spend over \$1,000 each month on services and supports related to their child’s disability that are not covered through government funding; and
 - ◆ 32 percent of caregivers report that they had to pay for their child’s assessment for diagnosis – costing up to \$4,000 or more;
- 32 percent of caregivers have had to apply to charities over the past three years to help pay for services and supports for their child and another 24 percent report that they would apply if they were eligible; and
- 56 percent of all caregivers reported that they have to repeatedly complete paperwork to access services across systems ‘quite often’ or ‘very often’ each year.

Breaking the Silos

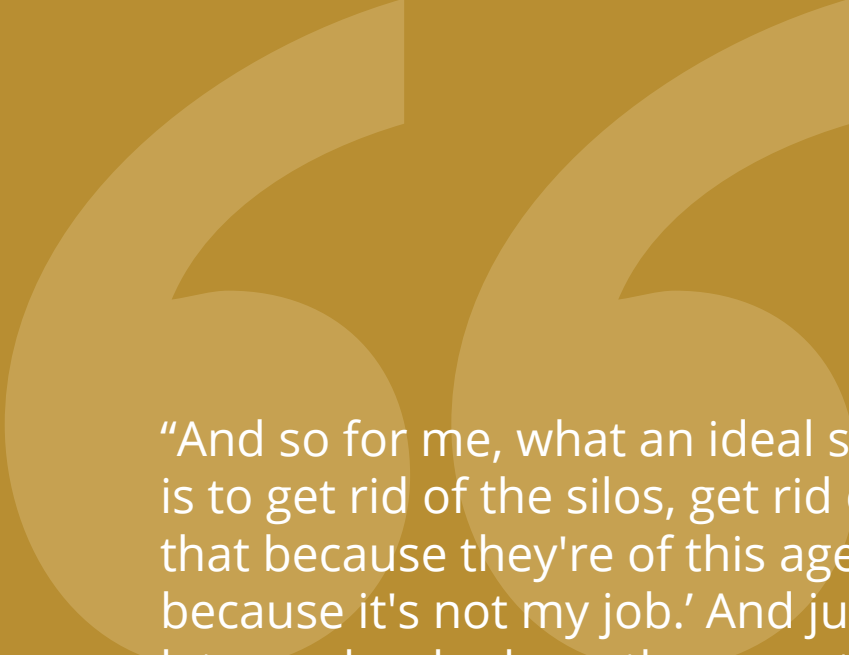
In *Don't Look Away*, it was revealed that the persistent silos and lack of interagency, intersectoral, interdisciplinary and inter-ministerial information-sharing, coordination and collaboration have long characterized the child welfare system. It is obvious that we need to break down these silos, but doing so must start at the top. In the RCY commissioned report, *Key Components of Effective Service Delivery for Children and Youth with Support Needs and Their Families: A Research Review and Analysis* by Dr. Pat Miranda, collaboration across government departments and ministries was specifically identified as a key component for effective disability service delivery in 61 percent of the research studies that were examined. The research is clear: collaborative government efforts make a difference in the daily lives of children and their families.

For years now, the B.C. government has acknowledged the importance of cross-ministry collaboration for children and youth with disabilities and has attempted to improve cross-ministry collaboration.

- In 2009, the government released the CYSN Framework for Action, which outlined values and strategies for collaborative work among health, education, and social service sectors to create an integrated, accessible continuum of quality services.⁴⁷
- In 2012, government announced the creation of a cross-ministry group to explore ways that ministries and government agencies can better collaborate in the provision of supports for people with disabilities.⁴⁸
- In 2013, the government announced a Cross-Ministry Disability Strategy Reference Group, comprised of 18 assistant deputy ministers, to explore ways to better collaborate in supporting accessible, inclusive communities for people with disabilities.⁴⁹
- In 2021, B.C. passed a new provincial law, the *Accessible B.C. Act*. This Act provides a framework to identify, remove, and prevent barriers to accessibility and enable the development of accessibility standards and new accessibility requirements for government.⁵⁰

Given the years of work on cross-ministerial coordination across sectors, one might expect that B.C. families with children and youth with disabilities have felt the impact of this work in their daily lives. However, this is not the case.

Despite all of this work, when MCFD released a service description for the new CYSN framework in April 2022, which was described as guiding “more accessible decision-making, policy, and system changes for children and youth with support needs and their families” there was no mention of cross-ministerial coordination.⁵¹



“And so for me, what an ideal system would look like is to get rid of the silos, get rid of the, ‘oh, we can't do that because they're of this age’ or ‘we can't do that because it's not my job.’ And just blur those lines, like let people who have the expertise provide the expertise and not have to worry about some of the other things – the politics for lack of a better term. No silos would be awesome.”

– Parent, RCY Engagement Session

“We shouldn't be suicidal before we get help. I don't think as parents we should become professional advocates for our kids. We are all out here teaching each other and our service providers about what's available.”

– Parent, RCY Engagement Session



Collective Responsibility:

Support Families – Family Support and Setting Children Off On the Right Course

In *Don't Look Away*, the Representative recommends that all ministries and public bodies that have important contributions to make to child well-being participate in a province-wide Keeping Families Safely Together dialogue, hosted by RCY, to build a cross-ministerial commitment and approach to wrap-around support for families to care for their children.

Children and Youth with Disabilities Call to Action:

Fund an equitable and resourced system of care that families can easily navigate.

The average person living in B.C. probably thinks that children and youth with disabilities and their families have access to the services and supports they need to thrive; most likely, they assume that, 'It may be a little tough sometimes to get services, but in the end, you get them.' However, for the majority of B.C. families who have children with disabilities, access to services is not guaranteed. Getting on a waitlist to access services is not a given and, in many cases, the services are not accessible because they simply do not exist.

Even families whose children do have access to government-funded services such as those in the MCFD CYSN system have told RCY that they still struggle and fight every day to get what their children need. They tell us that they are often forced to focus on their child's weaknesses and emphasize how poorly their child is doing because if they talk about their child's strengths and assets, services may be denied. The RCY survey revealed that 62 percent of families reported that they have been denied services and supports at least once and some as many as 10+ times.

“The public sense is that because we have universal healthcare that kids with disabilities get what they need to thrive, but they don’t.”

– Parent, Disability Summit

“Education and health..... is a service and it costs money and I wish that we as a society could somehow manage to see that as not a bad thing. This isn’t a profit or business that we’re running. We’re not trying to (take) every dollar, we’re trying to give people what they need. So. I don’t know, I think as Canadians we actually have a lot of room to grow in terms of how we serve people with disabilities.”

– Parent, RCY Engagement Session

“(My child) was denied (mental health services) because my child didn’t have a diagnosis at the time and the case wasn’t severe enough.”

– Parent, RCY Survey

“The reasons given for all (the service denied including respite, housekeeping, support worker, and childcare subsidy) was that there isn’t enough funding, and our family wasn’t in enough of a crisis, primarily because we have 2 parents.”

– Parent, RCY Survey

“At Home Program denied us because I verbally said my son can pull a sock off.”

– Parent, RCY Survey

“There is way too much emphasis on IQ. Many services in school and community are being denied because a child has a normal IQ. Being able to do academic work does NOT mean a child or teen is functioning socially, emotionally, or able to navigate the community on their own. That is an Ableist, outdated system.”

– Parent, RCY Survey

The State of Services

Even for families who do receive government disability services, significant challenges persist. RCY found that access to services does not necessarily mean that children are receiving what they need. In fact, only 32% of survey respondents agreed that the services they are receiving meet their child's needs.

While some families expressed gratitude for the services they do access:

“I am grateful for the supports that we currently access. I feel my child has progressed well with the flexibility of her ministry supports as well as the supports through her homeschool.”

– Parent, RCY Survey

Far more families shared that services are inaccessible in a timely manner, unavailable in their communities, or provided too late to make a difference. Many reported receiving fragmented or inconsistent therapy, such as group therapy or “blocks” of intervention (e.g., 4 months of therapy followed by 4 months with no services). This inconsistency often halts progress just as children begin to improve.

“SLP (Speech-Language Pathology) supports are almost non-existent, & when they are provided it's infrequent & with such little time allocated that the child is unable to make significant progress, or even keep currently levels of speech.”

– Parent, RCY Survey

“Very limited providers within our City. Basically, non-existent for PT (Physiotherapy), OT (Occupational Therapy) and BI (Behaviour Intervention). Have to travel to neighbouring communities IF we can get appointments.”

– Parent, RCY Survey

Again, respite services were another common area of frustration, with families highlighting limited availability and inconsistent access.

“Respite is helpful but is still a small drop in the very deep bucket of need. More in-house respite options need to exist where a parent could feel it is safe to leave their child for a night or two so they can have real rest including a proper night of sleep, but these do not seem to exist across the board with services varying greatly from region to region. Burnout is very, very real.”

– Parent, RCY Survey



“Respite. I was told that my non-verbal ASD son had to wait until another child ages out of the system. It’s been over 3 1/2 years and (we’re) still waiting. I’m beyond frustrated!!!”
– Parent, RCY Survey

Many families also pointed out the inadequacy of group therapies compared to individualized interventions:

“Seeing an SLP in a group for 20 mins a week (if you’re lucky) is not even slightly comparable to private therapy.”
– Parent, RCY Survey

“One parent in the pilot program said her child was only offered two group OT sessions in one year. That is ridiculous, as OT is usually 1:1 and requires weekly visits to be able to be successful.”
– Parent, RCY Survey

Even families accessing programs like Autism Individualized Funding or the At Home Program face barriers. Over 50% of families surveyed who access autism funding reported being unable to use their funding to meet their child’s needs. Barriers included: (1) difficulty finding qualified service providers, particularly in rural and remote areas; (2) high turnover and unreliability of providers;

(3) financial strain, with funding misaligned with actual service cost; (4) administrative burdens, such as delays in processing payments and the responsibility to find, hire and retain providers on their own; and (5) long waitlists for private service providers.

For families accessing the At Home Program, the challenges were similar. While the program provides funding for medically necessary equipment, it often falls short of covering associated costs. One parent in the Northwest shared an example of needing to self-fund repeated travel to Vancouver for their child’s leg brace adjustments. The At Home Program covered the cost of the braces but not the adjustments, so they had to pay for three visits to Vancouver. Noting that they were fortunate they had the means to pay for the travel whereas many other families may not.

Another family reported significant financial strain when funding that did not cover medically necessary equipment costs for their child pushed them further into debt. They received \$5,000 for a chair that cost \$8,500 and \$5,000 for a bed that cost \$10,000 and reported that coming up with the \$8,500 difference was no easy task.

Families Need Support, Not Judgement

Many families expressed exhaustion, frustration, and a sense of abandonment when they repeatedly sought help only to face silence, rejection, or judgment.

“There should be regular meaningful check-ins with families to see if they need help, i.e., with paperwork, navigating systems etc. We are left on our own, (busy, working and juggling multiple priorities) and struggle to reach out for help.”

“

– Parent, RCY Survey

“(We need) more therapists available for our kids, more psychologists and psychiatrists available and more funding for them. And every time our FASD kids confabulate we wouldn’t be investigated. We need help not judgement!”

– Parent, RCY Survey

The voices of families are clear: services need to be timely, accessible, and responsive to each child’s and family’s unique needs. Without this, families remain overwhelmed, children’s progress is stalled, and a broken system continues to fail those it is meant to support.



The Impact of Current Services

RCY looked back over the years and asked: “Over the past 18 years – the lifetime of childhood – what has been the state of services for children and youth with disabilities in B.C. and have the available services made a difference in the lives of children and their families?”

As stated earlier, the bulk of services for children and youth with disabilities and support needs has traditionally been held by MCFD within the CYSN system. Although the analyses that follow focus on MCFD and the CYSN system specifically, they should be viewed as examples of gaps and inequities that can occur across multiple ministries, health authorities and systems.

We start by examining government expenditures for CYSN services provided to us from MCFD between 2006 and 2024 – over 18 years.⁵² During these years, funding for CYSN services increased from \$216M (2006) to \$627.6M (2024), a rise of \$411.1M or 190 percent. Although RCY acknowledges the funding growth, families report that it has had little impact on their daily lives. In fact, the RCY Survey found that:

- 83 percent of all families said that CYSN services have stayed the same or gotten worse over the past 3 years;
- 46 percent of the families said that access to supports and services for their child have worsened in the past 3 years;
- Only 32 percent of all families agree that the services they are receiving met the needs of their children;
- Only 6 percent of families report that they felt confident that they will receive the out-of-school services in the next 1 to 3 years; and
- Only 7 percent of caregivers report that they felt confident they will receive the in-school services that they need in the next 1 to 3 years.

CYSN social workers who responded to the recent RCY Workforce Survey also expressed their concerns:⁵³

“There are not enough supports available to the families who need it. Waitlists are sometimes years long. This does not help the children and youth we work with. Families are placed at risk of protection issues because of the lack of supports available.”

– CYSN Worker, RCY Workforce Survey

Given these insights, RCY wondered, “If there are increases in CYSN service expenditures each year, but we consistently hear that children and youth with disabilities are being left out, where is all the new CYSN money going? And, equally important, how many children and youth are being left out of receiving services and for how long has this been going on?”

Who is and Who is Not Receiving Services?

This question, unfortunately, is not so easily answered. Government news releases often suggest that the additional funding allocated to CYSN is resulting in service provision to more children:

- July 31, 2008: “Government has more than 90 programs and services for children and youth with special needs at a cost of over \$500 million, and families have told us that navigating those services can sometimes be a challenge,” said Minister Christensen. “This grant will help us map services across the province so we can then enhance the system and better allow more families to easily access the right services at the right time.”⁵⁴
- Sept. 16, 2009: “The Ministry of Children and Family Development’s budget for autism intervention and funding programs is more than 10 times the 2001 budget of \$4.1 million, totaling more than \$46 million in 2009-10, including a \$1.6 million increase this year. As a result of these budget increases, more than 6,000 children and youth diagnosed with ASD and their families are served now, compared to only a few hundred prior to 2000.”⁵⁵

- July 18, 2019: “More than 1,300 additional families with children who have special needs are benefiting from respite services by qualified caregivers, thanks to this year’s program expansion.”⁵⁶

However, RCY’s analysis found that, over the past 18 years, nearly half (48 percent) of the spending growth went to diagnostic-specific, demand/caseload driven programs, including residential care for children and youth with disabilities who are in care; At Home medical benefits; and autism funding – meaning the majority of additional CYSN funding was either for a select group of children and youth who had the “right” diagnosis or who were deemed to have the “right” eligibility requirements or who were in care and under the responsibility of government. The remainder of the 190 percent growth increase was allocated to require collective agreement increases (24 percent) and respite rates, leaving only 28 percent to fund new growth in services to address the increasing demand for children and youth with disabilities and their families over the last 18 years.^{57,58}

So, next we wanted to know that given an only 28 percent growth increase over the last 18 years, are more children and youth, beyond those who meet specific eligibility requirements in demand-driven programs, being served in the CYSN system?

Are “More” Children Being Served

We started by looking at the number of children and youth with disabilities that MCFD serves. The Office found that the CYSN caseload numbers reported in the MCFD’s own Estimates Notes contradict the idea that more children are being served.⁵⁹ In fact, these documents report that there was no increase in the number of children and youth accessing CYSN services from 2011 to 2019 – with the number served remaining at “approximately 30,000” in each of those years. It was only reported in the MCFD 2024 Estimates note that the number of children and youth supported by MCFD CYSN programs and services increased to over 40,000.

The Estimates notes also reveal that MCFD has known for years that there are more children and youth with

support needs in B.C. than are being served by the MCFD CYSN system. For example, the 2014 MCFD Estimates Fact book stated – there were “approximately 61,600 children and youth with significant special needs in B.C.” while stating that only “30,000 children and youth with special needs access ministry intervention and support services between the age of birth up to the age of 19.” The 2024 MCFD Estimates note stated the number of children and youth supported by MCFD CYSN programs and services to be over 40,000, but also included the statement that there are “approximately 103,000 children from birth to age 18 (who) may have a support need.”



Collective Responsibility: Be Accountable

In *Don't Look Away*, the Representative recommends that the Government of British Columbia develop a child well-being accountability and data plan, as a component of the Child Well-Being Strategy and Action Plan, to ensure that child well-being outcomes are being measured and reported on for all children, with particular attention to those children and families experiencing the greatest inequities in the province of B.C.

Children and Youth with Disabilities Call to Action: Develop strong data measurement tools that allow us to know exactly who we need to serve, who is being served and how best to serve them.

Don't Look Away illuminated, through the sacred story investigation, that not only did the child welfare system utterly fail a young person in the final months of their life, but the system had also been failing that child and their family for years. As RCY learned more about this story, there was widespread outrage and distress and multiple calls for further “accountability” and consequences. However, it became clear that “accountability” did not just rest with one person, organization or Ministry. The whole system itself was fractured and, to better understand what led to the poor practice and missed opportunities exemplified in the sacred story investigation, we needed to know more about how these systems could be held accountable

– including understanding the outcomes, positive or negative, that children, youth and their families experience within these systems. In essence, we need more data in the form of a robust, multi-faceted child well-being outcome measurement framework that involves all ministries and public bodies who play a part in the lives of young people and their families. We must better understand what is helping to improve child well-being and what is not. Only with better data can informed decisions be made, especially for children and youth with disabilities and their families who often require assistance and services from multiple public bodies.

The Gaps in the Data

In preparing this spotlight we wanted to highlight what we thought would be straightforward statistics – how many young people in B.C. are living with disabilities, how many require supports and services, and how many are receiving supports and services? We quickly realized that these numbers are not readily available and so we undertook to do the calculations ourselves (See Appendix A). RCY estimates that there are over 120,000 children and youth with disabilities in the province and that each year, between 55,000 and 83,000 children and youth with disabilities and their families are likely not receiving the publicly funded supports and services that they need through Ministries like Children and Family Development, Health, Education and Childcare, Housing, and others.^{60,61}

In reality, due to the inadequacy of government data across ministries on how many children and youth with disabilities need services versus how many are receiving services, the analysis in this spotlight cannot definitively report the percentage of the 83,000 children and youth with disabilities that require, for example, MCFD CYSN specific services and supports versus those who may be better served through other cross-sector publicly funded services. In essence, this reinforces

what RCY has been highlighting for years: the need for better data. This recommendation was explicitly made in *Alone and Afraid* in 2018 and was most recently included in *Don't Look Away*.⁶² We need better data and analysis of needs, services, delivery and outcomes so that we can make better and more impactful policy and program decisions.

Data gaps are also prevalent in other service areas. For example, currently there is no data to inform optimal wait times across service sectors such as assessment for diagnosis, access to therapies, or access to respite in B.C. We do not have accurate data and forecasts to plan for services and supports for children and youth with disabilities and other complex support needs across the province.⁶³ We also do not know what services are working for children and youth with disabilities and their families and what are not. There is no cross-government outcome-based framework to know what outcomes children and families experience when they receive services. Accurate data are essential; without an understanding of the population being served, government will not be able to adequately plan for the well-being of children and youth with disabilities and their families across publicly delivered services in B.C.

Where Do We Go from Here?

The children and youth with disabilities system in B.C. is clearly in need of significant reform, and the government appears to agree. In 2018, government consultations began for a new children and youth with disabilities framework, culminating in a proposed model in 2021. Unfortunately, the proposed model fell short and faced considerable backlash from Indigenous leaders, community representatives, parents/caregivers of autistic children, and numerous community, disability and professional organizations. Consequently, the wait for meaningful change drags on, leaving tens of thousands of children with disabilities and their families left behind with little to no access to public services.

RCY has heard loud and clear from thousands of families across the province that they continue to feel underserved, overburdened, and frustrated by a lack of adequate services, funding, and support. They tell us that they urgently need mental

health and respite services for the well-being of themselves and their children. They tell us that they feel isolated, burned out, unsupported, and that they are deeply concerned for the future of their children. They call out for improved access to individualized services, and they request equitable distribution of resources for all children with disabilities, not just those that meet specific eligibility criteria or those with specific diagnoses.

In essence, through our engagement, families have told us that they need a system that is well-funded; provides sustainable and coordinated supports; accommodates choice through individualized, family-centred care; is proactive, rather than reactive; is equitable, inclusive, needs-based, accountable, and flexible; is easy to navigate; provides timely and equitable access; is culturally safe, informed and competent; and is based on the principles and actions of trauma-informed care.

How Do We Get There?

A Pathway Forward

Reforming service systems does not happen overnight. It is a complex and multifaceted process that involves multiple levels of government, crosses service sectors, and differs between communities. However, as Elder Shane Pointe, a Coast Salish Knowledge Keeper, wisely reminds us: "We cannot use of the term 'complex' as an excuse to not move forward."⁶⁴ So, let's move forward.

In addition to the three calls to action outlined in this spotlight, RCY urges the government to address the immediate service needs of children and youth with disabilities and their families.



What Families Tell Us Would Make a Difference Right Now

RCY urges government to immediately address the following service needs:

Navigation/Case Coordination

The top service priority families shared with RCY was their need for service navigation and case coordination. One parent highlighted this in the RCY survey, stating:

“I need a clear vision of what the future supports of my child are. I would like to have an experienced social worker or personal to help me navigate the work, life, and public support for certain ages in the future for my child.

It would be great to access generalists who can support families with any questions or concerns related to child development, and help them navigate the system as a whole vs having to go to Childcare resource and referral, an intake worker, a navigator, a supported child development consultant, an intake again, another social worker. Too many people to tell stories to.”

– Parent, RCY Survey

Out-Of-School Service Priorities

In the RCY survey, families were asked: “What out of school services and supports do you or your children need right now?” Responses revealed that the top need for children under the age of 13 is therapies (specifically, Speech-Language Therapy; Occupational Therapy; Physiotherapy not funded through Autism Funding Programs) (see Table 1). For children over the age of 13, the most critical need was counselling to support a youth’s mental health.

It is interesting to note that the remaining top five service needs go beyond therapeutic and child-centered services and highlight the importance of wraparound supports that benefit the entire family unit. These services include mental health supports for all members of a child’s caregiving circle (e.g., relatives, siblings, others living in your home, etc.) and access to inclusive community and recreational programs, as well as spring and summer programs. These types of programs do more than provide children with social and developmental benefits which foster their sense of belonging – they also give caregivers much-needed respite, lifting up the family as a whole.

The RCY Survey also asked families: “If you had to choose, which one of

the following out of school services and supports would result in an immediate improvement in the life your child/ren in the next 6-12 months?" Again, families with children aged 0-12 overwhelmingly prioritized therapies, while families with youth aged 13-18 indicated that counselling was their number one immediate service need.

In-School Service Priorities

The RCY survey asked: "What in-school services and supports do you or your children need right now?" Responses revealed that the top in-school service needs were occupational therapy for children aged 6-12 and Focused Math Instruction for youth aged 13-18 (see

Table 2). The remaining top five needs included focused literacy and writing instruction, access to Educational Assistants in the classroom, and the need for timely psychoeducational assessments to inform educational planning.

When we asked families to choose one in-school service and support that would result in an immediate improvement in the next 6-12 months, an Educational Assistant emerged as the top choice for both age groups. It is clear that more Educational Assistants are needed to support classroom teachers so that children can succeed within the education system.

What Families Tell Us Would Make A Difference Right Now: Summary

Navigation/Case Coordination

- Community-based case coordinator assigned to a family from first concern to adulthood.

Out-Of-School Service Priorities

- Therapies (specifically, Speech- Language Therapy; Occupational Therapy; Physiotherapy not funded through Autism Funding Programs);
- Counselling to support a youth's mental health;
- Mental health supports for all members of a child's caregiving circle (e.g., relatives, siblings, others living in your home, etc.);
- Access to inclusive community and recreational programs; and
- Spring and summer programs.

In-School Service Priorities

- Educational Assistants in the classroom;
- Occupational Therapy;
- Focused Math Instruction;
- Focused literacy instruction;
- Focused writing instruction; and
- Access to timely Psychoeducational Assessments to inform educational planning

Table 1:
Top Five Out-of-School Services Needed Now⁶⁵

	Ages 0-5	Ages 6-12	Ages 13-18	All Respondents
1	Therapies*	Therapies	Counselling	Counselling
2	Parent/ Family Support (e.g., parent training/coaching, supports for siblings, etc.)	Mental Health Supports for Caregivers and Family	Community and Recreation Programs	Therapies
3	Mental Health Supports for Caregivers and Family	Spring and Summer Programs	Out of School Tutoring	Mental Health Supports for Caregivers and Family
4	Community and Recreation Programs	Counselling	Spring and Summer Programs	Spring and Summer Programs
5	Spring and Summer Programs	Community and Recreation Programs	Therapies	Community and Recreation Programs

* Therapies were defined as “Speech-Language Therapy; Occupational Therapy; Physiotherapy not funded through Autism Funding Programs.”

Table 2:
Top Five In-School Services Needed Now

	Ages 0-5*	Ages 6-12	Ages 13-18	All Respondents
1		Occupational Therapy	Focused Math Instruction	Occupational Therapy
2		Focused Writing Instruction	Focused Writing Instruction	Focused Writing Instruction
3		Focused Literacy Instruction	Occupational Therapy	Focused Math Instruction tied with Educational Assistant
4		Focused Math Instruction	Focused Literacy Instruction	Focused Literacy Instruction
5		Educational Assistant	Psychoeducational Assessment	Psychoeducational Assessment

* Omitted as majority are not in school

Children and Youth with Disabilities Service Framework Guidelines

Successful transformation of the children and youth with disabilities system of services in B.C. is possible but action towards long-term change must start now. RCY engagement efforts over the past two years, including the RCY-commissioned report, [Key Components of Effective Service Delivery for Children and Youth with Support Needs and Their Families: A Research Review and Analysis](#) by Dr. Pat Miranda and the RCY Survey completed by 1,160 families, revealed 11 essential guiding principles for the development of a successful children and youth with disabilities service system. We urge government adopt and address each of these guidelines:

1. **Sufficient and Equitable Funding**
The system must allocate funding equitably and ensure that there are sufficient resources to meet the needs of all children and youth with disabilities.
2. **Cross-Ministerial and Sectoral Collaboration**
The system must have effective collaboration across government ministries and service sectors to ensure streamlined and coordinated care.
3. **Wraparound Family-Centered Care**
The system must have services that focus on both child and family well-being and reach out to offer support when and where it is needed most.
4. **Accessible and Easy-to-Navigate Services**
The system must be user-friendly and minimize barriers across service lines.
5. **Community-Based and Flexible Solutions**
The system must promote local, community-driven solutions to service delivery and provide families with timely connections to community networks and resources.
6. **Functional Needs-Based Services, Not Diagnosis-Based**
The system must allow access to services based on functional needs. We note that diagnoses are helpful for many families and individuals, however, we have learned that meeting children's functional needs with or without a diagnosis is key.
7. **Choice and Individualized Care**
The system must provide families with options for how services are funded and delivered, reflecting their unique preferences and circumstances.
8. **Competent and Quality Service Delivery**
Systems must ensure that service providers are adequately trained, culturally competent, and capable of delivering high-quality care.
9. **Cultural Safety**
The system must integrate Indigenous and other cultural values and practices to ensure inclusivity.
10. **Trauma-Informed Care**
The system must provide care that addresses and mitigates trauma, avoiding practices that may exacerbate it.
11. **Accountability and Transparency**
The system must hold itself accountable to children, families, and the public, with measurable outcomes and clear communication.



Key Components for Successful Service Delivery

Cross-Ministerial/
Sectoral
Collaboration/ Wrap
Around Supports

Mental Health
Supports for Child
and Family

Increased and
Equitable Funding
for Children
and youth with
disabilities

Accessible and
Inclusive Childcare

Protocols to share
Information Across
Service Sectors

Improvements in
School Supports

Community-Based
Procurement
Practices

Improving Quality
of Existing Service
Providers/Training

Transparent
Funding Formula

Coordination of
Services Across
Therapies

Accurate Data on
Numbers Requiring
and Receiving
Services

Improving
Community Inclusion
in Recreation and
Spring and Summer
Programs

Timely Diagnostic
Assessments

Culturally Safe and
Trauma Informed
Practices & Embedding
Indigenous Culture,
Values, and Practices;
"Two-Eyed Seeing"

Increasing
Professional Service
Capacity – Including
Expansion of Rehab
Assistants

Conclusion

This spotlight underscores the urgency of addressing the unmet needs of the over 120,000 young people living with disabilities in B.C. It paints a picture of a system that is currently unable to meet the needs of tens of thousands of young people. The systemic changes necessary for comprehensive support have been delayed for far too long.

In the meantime, the opportunities for children and youth with disabilities in B.C. to receive the services they need to thrive in childhood have been lost. Children are being left behind. Each year, tens of thousands of children and youth with disabilities have gone underserved or left out of accessing the cross-ministry services and supports that they need to thrive.

The tragic experiences of the many young people presented in *Don't Look Away* highlight the inequities that children and youth with disabilities and their families face. For 18 years, since the inception of RCY in 2007 we have been calling for change in our province – that is the lifetime of a child. RCY again calls on government to deliver and take immediate and long-term actions to fund a cohesive, accessible system for all children and youth with disabilities and their

families no matter a child's diagnosis; no matter where they live; and no matter what service delivery system they require (e.g., in-school services, out-of-school/community services, medical services, transportation and housing services, etc.).

Children and youth with disabilities and their families desperately need a system that is easy to navigate and wraps around the whole child and family; they need a system that is funded and resourced to address the needs of ALL children and youth with disabilities in B.C; and to do this, they need government to develop strong data measurement tools so that we know exactly who we need to serve and how best to serve them.

With government's commitment to the Collective Responsibilities and recommended actions set out in *Don't Look Away*, along with the recently concluded community engagement work for a children and youth with disabilities framework, there is a significant opportunity to redesign systems of care that uphold the rights of children and youth with disabilities and ensure that they are able to reach their full potential. The time to act is now.

Relevant Recommendations from Previous RCY Reports

The findings highlighted in this spotlight are not new. The Representative has previously made numerous recommendations to address these issues. As mentioned, in *Don't Look Away*, the RCY proposed five collective responsibilities aimed at achieving long-term, transformational change from an outdated and often ineffective child welfare system to one focused on child well-being. The government has agreed to implement the actions in each of these responsibilities. Therefore, rather than introducing new recommendations in this spotlight, we presented three of the collective responsibilities from *Don't Look Away* and emphasized the specific actions needed to uphold the rights of children and youth with disabilities and their families as these responsibilities are implemented.

That said, while examining the *Don't Look Away* collective responsibilities, it became evident that many of the required actions for an effective child well-being system are supported by the ongoing progress toward past recommendations from previous RCY reports, including *Alone and Afraid* (2018), *Excluded* (2021), and *Toward Inclusion* (2023). Notably, the timelines for implementing these RCY recommendations regarding children and youth with disabilities remain outstanding (see [Recommendations | Office of the Representative for Children and Youth - RCYBC](#)). Therefore, we have restated the past RCY recommendations from these reports as a key reference for future action toward an effective child well-being system that leaves no-one behind.

It is essential to reiterate that although many of our past recommendations are directed towards specific ministries, the goal is to support the well-being of the entire child and family and that requires a whole government approach. Children and youth with disabilities, along with their families, depend on services from multiple service streams. Therefore, the responsibility to create and sustain a system that allows every child and family to thrive is a collective one.

The Office of the RCY is committed to being part of this collective effort. We stand ready to collaborate with the government to prioritize and streamline the implementation of past recommendations. Together, we can take meaningful, tangible action to build a system that upholds the rights and well-being of children and youth with disabilities and their families.

Don't Look Away Collective Responsibility #1 Focus on Child Well-Being

Previous Relevant Recommendations

Alone and Afraid Recommendation #3: That MCFD take the lead in working with the Ministry of Health and the Ministry of Education to develop an integrated service delivery model that enables appropriate information-sharing between service providers. This model would ensure that children and youth receiving special needs services through MCFD can be supported by a case coordinator who is responsible for navigating access to, and provision of, all necessary services. The case coordinator to remain assigned to the child to ensure appropriate services and facilitate successful transition to adulthood. MCFD to lead development of a comprehensive plan by the fall of 2019 and seek funding and begin implementation of the plan by April 2020.

Alone and Afraid Recommendation #10: That the Ministry of Health and MCFD develop a plan to ensure early identification, timely assessment and appropriate and accessible supports for children under six-years-old with signs of developmental delay.

Alone and Afraid Recommendation #11: That the Ministry of Health take steps to incrementally decrease the wait times to three months for completed assessments of autism and complex behavioural developmental conditions across the province.

Excluded Recommendation #4: As a first step toward realizing fundamental changes in practice that address racism, stigma and bias, MCFD, in collaboration with DAAs, community service agencies and caregivers, to conduct a review of existing FASD awareness training and the training needs of all front-line staff working with children and youth with FASD.²²⁴ MCFD, working with DAAs, to use this review to support the development of evidence-based, culturally attuned and regularly updated training materials that ground a required training program for current staff across the range of MCFD service lines and, in particular, CYMH, CYSN, child welfare and youth justice. This awareness training should then be incorporated into basic entry training for newly hired staff and made accessible to community service agencies and caregivers. MCFD to complete the reviews and curriculum development and begin training by March 31, 2022 and complete training of all relevant ministry and agency staff by March 31, 2023.

Excluded Recommendation #5: That the Ministry of Mental Health and Addictions (MMHA), in collaboration with MCFD, DAAs and the Ministry of Health, 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 Pathway to Hope for implementation. MMHA to complete the review and plan by March 31, 2022, with MCFD and Health beginning the implementation of new service approaches and enhanced services by Oct. 1, 2023, and completing implementation by March 31, 2024.

Excluded Recommendation #6: That the Ministry of Health incrementally reduce wait times for complex developmental behavioural conditions (CDBC) diagnostic clinics, and also secure additional resources to provide for periodic follow-up assessments, at key development stages from infancy through to adolescence. The Ministry of Health to reduce wait times to nine months by March 31, 2022; to six months by March 31, 2023; to three months by March 31, 2024; and thereafter increase capacity to provide for follow-up assessments.

Excluded Recommendation #8: That the Ministry of Health conduct an assessment of existing FASD awareness training and the training needs of appropriate front-line staff working with children and youth with FASD, leading to the development of evidence-based, culturally attuned, Nation-specific and regularly updated training materials that ground a mandatory training program for current staff across the range of health services. Ministry of Health to complete the assessment of existing FASD awareness training by March 31, 2022. Sequentially, the Ministry of Health to identify appropriate priority front-line providers to receive training, by Sept. 30, 2022, and develop training and access to training by Sept. 30, 2023.

Toward Inclusion Recommendation #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.

Don't Look Away Collective Responsibility #2 Support Families

Previous Relevant Recommendations

Alone and Afraid Recommendation #2: That MCFD take immediate steps to improve the current accessibility of CYSN services and supports by providing respite within a reasonable period of time.

Alone and Afraid Recommendation #4: That MCFD ensure its children and youth with special needs training is mandatory for child protection staff. MCFD to ensure that all child protection social workers complete training by April 2020.

Excluded Recommendation #1: That the Ministry of Children and Family Development (MCFD) fully fund and implement a CYSN service framework and plan, fully inclusive of children and youth with FASD. The formation of the service framework and plan must extensively engage Delegated Aboriginal Agencies (DAAs) and all appropriate partners. This framework must articulate a comprehensive and accessible array of CYSN services, delivered based on both an assessment of functional needs and diagnosis and, therefore, fully including children and youth affected by FASD. MCFD to begin implementation by Sept. 30, 2021 and complete full implementation of the CYSN service framework and plan over a three-year period ending March 31, 2024.

Excluded Recommendation #2: Pending full implementation of *Excluded Recommendation 1*, that MCFD immediately include suspected or confirmed FASD, based on an assessment of functional needs, in the eligibility criteria for CYSN Family Support Services, thereby allowing children and youth with FASD and their families to access services available to others with specific neuro-developmental conditions. The ministry should seek appropriate funding to expand the capacity of these services to adequately support the number of newly eligible FASD families so that this recommended expansion of service eligibility does not lead to reduced services or longer wait lists for other CYSN families. MCFD to secure immediate funding enhancements and begin implementation of the expanded eligibility criteria by Sept. 30, 2021.

Excluded Recommendation #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. MCFD to take immediate action to ensure equitability and accessibility of the KWSP by Sept. 30, 2021 and complete the best practice review by March 30, 2022.

Excluded Recommendation #10: That the Ministry of Education update its Inclusive Education Policy and supporting documents and incorporate information to increase awareness and understanding of the specific learning needs of children and youth with FASD and related disorders into the supporting documents. Ministry of Education to update Inclusive Education Policy and supporting documents and incorporate information to enhance awareness of FASD and related disorders by Sept. 1, 2021

Toward Inclusion Recommendation #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.

Toward Inclusion Recommendation #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.

Don't Look Away Collective Responsibility #4 Be Accountable

Previous Relevant Recommendations

Alone and Afraid Recommendation #1: That MCFD undertake a comprehensive assessment of the actual need for CYSN services across B.C. and the capacity of the current system to meet those needs. This assessment to examine funding, staffing levels and workloads, program delivery and wait times. Findings to be used to inform comprehensive service improvements so all eligible children with special needs and their families receive culturally respectful, appropriate and timely services and supports. MCFD to complete the comprehensive assessment and plan by the fall of 2019, seek necessary funding enhancements and begin implementation of changes by April 2020.

Alone and Afraid Recommendation #6: That MCFD and the Ministry of Education develop practice guidelines and a joint protocol to address concerns of unexplained school absences and withdrawals with the view to supporting children, youth and families and addressing barriers to school participation. MCFD and the Ministry of Education to conduct this work in consultation with advocates/stakeholders from the Indigenous and special needs communities. MCFD and the Ministry of Education to complete this work by May 2019.

Alone and Afraid Recommendation #7: That the Ministry of Education establish mechanisms to enable local school districts to identify and do timely follow up when a school-age student is not registered in an educational program. Ministry of Education to complete this work by September 2020.

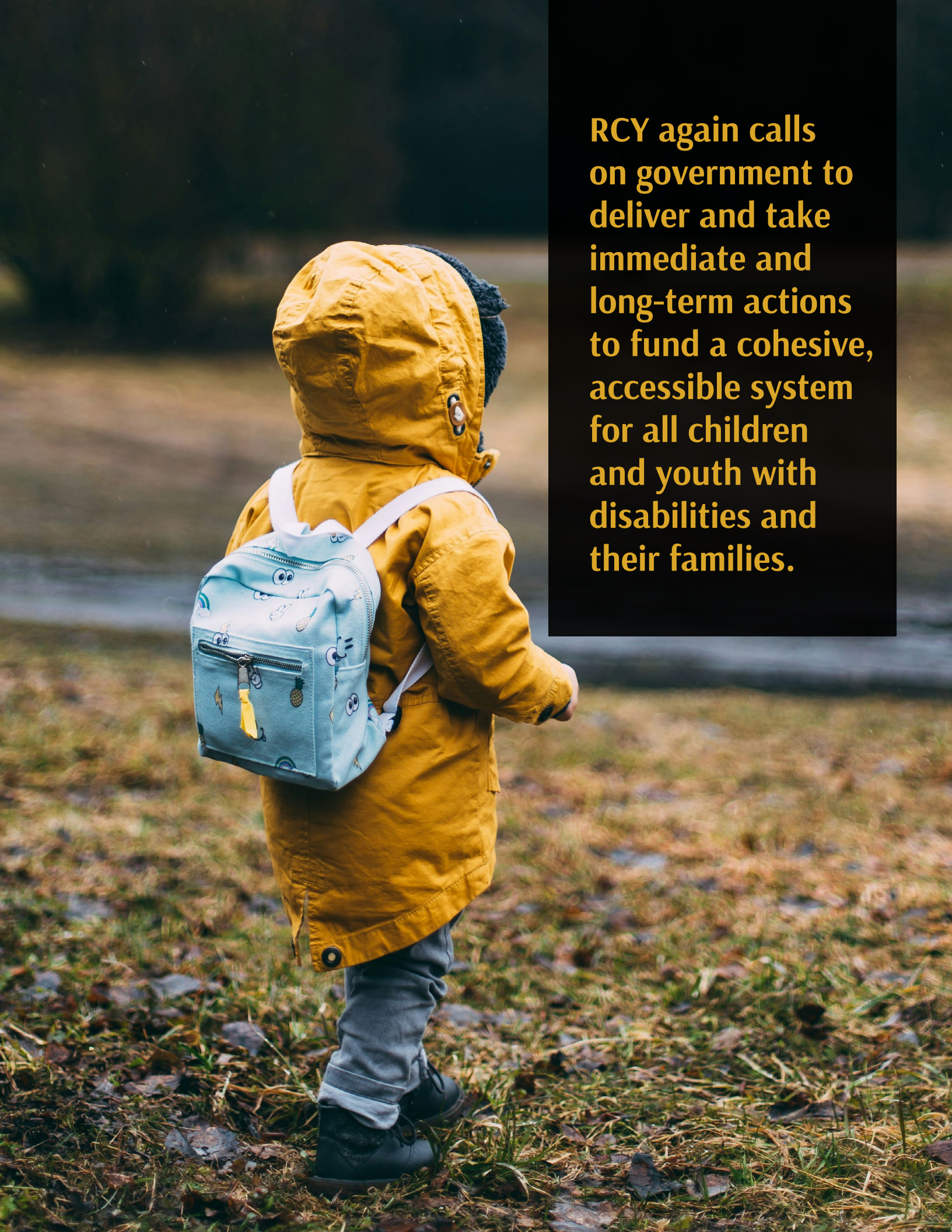
Alone and Afraid Recommendation #8: That the Ministry of Education determine how many students with special needs designations are being homeschooled and conduct a review to determine whether school districts should be offering additional support and guidance to these students. Ministry of Education to complete this work by September 2020.

Toward Inclusion Recommendation #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.

Excluded Recommendation #9: MCFD together with the Ministry of Citizens' Services to initiate the development of a cross-ministry plan, in collaboration with the ministries of Health, MMHA, Social Development and Poverty Reduction, and Education, and in association with ICFSAs, 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 special needs and their families, including those with FASD who are receiving services from these public bodies. The cross-ministry plan to be completed and implemented by April 1, 2022 and fully implemented by March 31, 2024.

Excluded Recommendation #11: That the Ministry of Education work with the British Columbia Council for Administrators for Inclusive Supports in Education (BC CAISE) to support staff training and development needs for educators and school staff who work with children and youth with FASD or suspected FASD, and their families, and build on evidence-based and promising practice approaches to better support inclusion and improved learning outcomes for children and youth with FASD. Ministry of Education to work with BC CAISE and partners to support the implementation of staff training and development to better support inclusion and improved learning outcomes for children and youth with FASD and related disorders by Sept. 1, 2022.

Toward Inclusion Recommendation #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.



RCY again calls on government to deliver and take immediate and long-term actions to fund a cohesive, accessible system for all children and youth with disabilities and their families.

Appendix:

Estimating the number of children in the province with a disability who require MCFD CYSN services; who received MCFD CYSN services; and who did not receive services from 2011 to 2023.

Data Scope:

Children and youth with disabilities and their families require services from a multitude of service streams including those within the Ministries of Children and Family Development, Education and Childcare, Health, Social Development and Poverty Reduction, and Housing, to name a few. However, the majority of out-of-school services for children and youth with disabilities in B.C. are provided within the Children and Youth with Support Needs (CYSN) system under the Ministry of Children and Family Development (MCFD). Access to many of these services requires a specific diagnosis or meeting eligibility criteria. The data analyzed below by RCY, while specific to MCFD CYSN services, serves as an example of the estimated number of children and youth with disabilities in the province left out of publicly funded cross-sector services.

The most straightforward way to estimate the number of children with disabilities is to multiply the estimated percentage of children with disabilities by the total population of children and youth. Therefore, to estimate the number of children and youth with disabilities in B.C. who require CYSN services as, we used two population percentage rates, 9.7 percent and 12.7 percent.

These two population percentage rates were the only ones that RCY could find within government records. The first percentage rate, 9.7 percent was provided through the administrative fairness process by MCFD.⁶⁶ However, according to new Canadian data, RCY believes the population percentage rate of 9.7 percent may be too low. For example, “according to the 2022 Canadian Survey on Disability (CSD),

more than one in four Canadians (27 percent) aged 15 years and older, or 8.0 million people, had one or more disabilities that limited them in their daily activities.”⁶⁷

Therefore, RCY also used the “students with disabilities/diverse abilities percentage of K-12 students” in provincial and public and independent schools of 12.7 percent from the Ministry of Education and Child Care (MECC) Estimates e-binder 2023 dated Mar 27, 2023.^{68,69}

To estimate the number of children and youth with disabilities in B.C. who receive CYSN services each year we used the year-over-year financial

data from 2011 to 2023 – a 13 year span.⁷⁰ Though an 18-year analysis (the lifetime of childhood) was the initial goal, data inconsistencies before 2010/11, partly due to CYSN services previously being run by Community Living B.C. (CLBC), made this unfeasible.

Table 3, on the following pages, presents the estimated number of children with disabilities in the province who may require MCFD CYSN services, using both the percentages 9.7 percent and 12.7 percent; those who received CYSN services, and those who did not receive services from 2011 to 2023.

Analysis

Regardless of which percentage is used (9.7 percent or 12.7 percent) as a proxy to better understand the service needs for children and youth with disabilities in B.C., it is clear that, year after year, the number of children not receiving appropriate publicly funded services and supports is very high. For example, using the 9.7 percent rate provided by MCFD, over 55,000 children, or 61 percent of those with disabilities, were likely not receiving the needed supports annually through MCFD CYSN services. While some may have received services through other channels such as education or health, the lack of cross-ministerial data makes it impossible to confirm this.

With the more realistic 12.7 percent rate, RCY found that the MCFD CYSN system served only approximately 29 percent of children and youth with disabilities annually. It is true that not all of the over 83,000 children and youth with disabilities will need the current suite of MCFD CYSN services offered. They instead may be better served through services provided by other Ministries such as Health and Education and Childcare may be more appropriate. But without accurate data across service sectors, the only thing we do know for certain is that far too many children and youth with disabilities have gone unserved for far too long.

Table 3:

Estimated number of children in the province with a disability who may require MCFD CYSN services; who received MCFD CYSN services;⁷¹ and who did not receive MCFD CYSN services from 2011 to 2023.

Year	Budget Year	Fiscal	Population - Estimated number of children with disabilities age 0-18 - prevalence at 9.7%	Population - Estimated number of children with disabilities age 0-18 - receiving services	Population - Estimated number of children with disabilities age 0-18 - NOT receiving services	% children with disabilities NOT receiving services
2011	2010	2010/11 baseline	88,104	30,000	58,104	66%
2012	2011	2011/12	88,058	30,045	58,013	66%
2013	2012	2012/13	87,659	29,961	57,697	66%
2014	2013	2013/14	87,266	30,298	56,968	65%
2015	2014	2014/15	87,373	30,045	57,328	66%
2016	2015	2015/16	87,643	30,422	57,201	65%
2017	2016	2016/17	90,886	31,628	59,259	65%
2018	2017	2017/18	91,283	33,349	57,934	63%
2019	2018	2018/19	91,572	37,354	54,218	59%
2020	2019	2019/20	91,499	36,363	55,136	60%
2021	2020	2020/21	90,974	37,616	53,359	59%
2022	2021	2021/22	90,760	40,259	50,502	56%
2023	2022	2022/23	92,866	43,337	49,529	53%
2024	2023	2023/24	97,757	47,721	50,036	51%
		Average	90,264	34,887	55,377	61%

Year	Budget Year	Fiscal	Population - Estimated number of children with disabilities age 0-18 - prevalence at 12.7%	Population - Estimated number of children with disabilities age 0-18 - receiving services	Population - Estimated number of children with disabilities age 0-18 - NOT receiving services	% children with disabilities NOT receiving services
2011	2010	2010/11 baseline	115,353	30,000	85,353	74%
2012	2011	2011/12	115,293	30,045	85,248	74%
2013	2012	2012/13	114,769	29,961	84,808	74%
2014	2013	2013/14	114,256	30,298	83,958	73%
2015	2014	2014/15	114,395	30,045	84,351	74%
2016	2015	2015/16	114,750	30,442	84,307	73%
2017	2016	2016/17	118,995	31,628	87,368	73%
2018	2017	2017/18	119,893	33,349	86,166	72%
2019	2018	2018/19	119,893	37,354	82,540	69%
2020	2019	2019/20	119,797	36,363	43,434	70%
2021	2020	2020/21	119,111	37,616	81,495	68%
2022	2021	2021/22	118,830	40,259	78,572	66%
2023	2022	2022/23	121,587	43,337	78,250	64%
2024	2023	2023/24	127,991	47,721	80,720	63%
		Average	118,181	34,887	83,294	71%

End Notes

¹ The number, 120,000, represents an estimate of all children and youth with a disability/support need under the age of 18 in BC. This estimate was calculated as follows: According to page 3 and 5 of the 2023 Ministry of Education and Child Care (MECC) estimate note, Advice to the Minister, titled “Students with Disabilities or Diverse Abilities-Public and Independent,” (received on June 29, 2023 through a section 10 request under the Representative for Children and Youth Act) 12.7 percent of students in public and independent schools in K-12 are identified as “students with disabilities/diverse abilities.” Therefore, by extrapolating the 12.7 percent to all children under the age of 19 and using the 2023 BC Population Estimates & Projections (shinyapps.io) which states that there were 972,582 children ages 0-18 in 2023, it can be estimated that there are 123,518 (952,582 x 0.127) children and youth “with Disabilities or Diverse Abilities” in B.C. RCY has chosen to use the MECC 12.7 percent as an estimate of the rate for all children and youth with disabilities across the province. Through the administrative fairness process, the Ministry of Children and Family Development (MCFD) identified that the MECC definition of students with disabilities/diverse abilities would be defined differently than MCFD’s (Children and Youth with Support Needs - CYSN) - eligible population. RCY believes that the MCFD, CYSN-eligible population does not encompass all children and youth with disabilities and that the MECC designations encompass a broader range of disabilities that may more accurately represent the disability population that may require or benefit from publicly funded services within the social, health or educational sectors. The MECC designations include the following inclusive education categories: physically dependant, deafblind, moderate to profound intellectual disability, physical disability or chronic health impairment, visual impairment, deaf or hard of hearing, autism spectrum disorder, intensive behavioural interventions or serious mental illness, mild intellectual disability, gifted, learning disability and moderate behaviour support/mental illness. NOTE: the designation of “gifted” was not excluded as according to Specialist Association of Gifted Educators in British Columbia (SAGE BC) “about 70 per cent of gifted kids have a “comorbidity,” meaning they also have learning disabilities or mental health issues like dyslexia or anxiety. A smaller but significant subset of gifted children are considered “twice exceptional” because they have autism or attention-deficit/hyperactivity disorder on top of being gifted ([Is Vancouver’s Program for ‘Gifted’ Children Unfair? | The Tyee](#)). The fact that MCFD and MECC have different definitions of children and youth with disabilities is another example of the lack of accurate data and cross-ministry consistency.

² Canada is a signatory to the [UNCRC](#) (United Nations Convention on the Rights of the Child) and [UNCRPD](#) (United Nations Convention on the Rights of Persons with Disabilities)

³ The RCY CYSN Check-In Survey was distributed through an on-line format with the option of completion by phone or a paper version. The purpose was to hear from families about their recent experiences accessing services and supports for children and youth with disabilities through the MCFD CYSN programs and other government-funded services. The target audience was ALL parents and families who care for children with support needs no matter if they are currently receiving government services or not. The link to the survey was posted on the RCY website and the survey was “advertised” through social media, in-person gatherings, and distributed to email listserves by family service organizations across B.C. The survey opened on October 13, 2023, and closed on November 30, 2023. Note: Preliminary results of the RCY CYSN Check-In Survey were used in the RCY report *Still Left Out: Children and youth with disabilities in B.C.* released on November 9, 2023.

⁴ Over the past six years, RCY has engaged with many disability organizations across the province. Most recently in June 2024, RCY co-sponsored a groundbreaking two-day, in-person disability summit, attended by 42 provincial organizations that represent children and youth with support needs.

⁵ [PowerPoint Presentation](#) (gov.bc.ca)

⁶ For the analysis in this spotlight, MECC designations were used to define children and youth with disabilities.

See end note 2.

For the RCY Survey in this spotlight, children and youth with disabilities were defined by families who indicated their child had one or more of the following diagnostic or suspected diagnosis categories: Apraxia; Attention Deficit Disorder/ Attention Deficit Hyperactivity Disorder; Autism Spectrum Disorder; Blind/ Visual Impairment; Cerebral Palsy; Complex Medical/Health Condition (e.g., seizure disorder, respiratory disorder, feeding disorder, etc.); Deaf/ Hard of Hearing; Down syndrome; Dyscalculia; Dysgraphia; Dyslexia; Epilepsy/Seizure Disorder; Fetal Alcohol Spectrum Disorder; Fragile X; Intellectual Disability; Learning Disability; Mental Health Condition (e.g., Anxiety, Depression, Obsessive Compulsive Disorder, etc.); Pathological Demand Avoidance; Rare Genetic Disorder; Tourette syndrome; and Other.

⁷ Source: [The disability rate in Canada increased in 2022](#) – Statistics Canada (statcan.gc.ca)

⁸ Multiple sources documented in the RCY Report: [Key Components of Effective Service Delivery for Children and Youth with Support Needs and Their Families: A Research Review and Analysis](#) February 2023

⁹ Source: [Pay Now or Pay Later: Autism Families in Crisis | Canada Commons](#)

¹⁰ Source: [The economic benefits of a fully accessible and inclusive Canada](#) (iwh.on.ca)

¹¹ Source: [The economic benefits of a fully accessible and inclusive Canada](#) (iwh.on.ca)

¹² RCY Reports: [Monitoring Brief System of Services for Children and Youth with Special Needs](#) February, 2008 [Update: System of Services for Children and Youth with Special Needs](#) September 2010; [Isolated and Invisible: When Children](#)

[with Special Needs are Seen but Not Seen; Still Waiting First-hand Experiences with Youth Mental Health Services in B.C.](#) April 2013; [Missing Pieces Joshua's Story](#) October 2017; [Alone and Afraid Lessons learned from the ordeal of a child with special needs and his family](#) December 2018; [Left Out: Children and youth with special needs in the pandemic](#) December 2020; [Skye's Legacy: A Focus on Belonging](#) June, 2021; [Excluded: Increasing Understanding, Support and Inclusion for Children with FASD and their Families](#) April 2021; [Still Left Out: Children and youth with disabilities in B.C.](#) November 2023; [Key Components of Effective Service Delivery for Children and Youth with Support Needs and Their Families: A Research Review and Analysis](#) February 2023; and [Toward Inclusion: The need to improve access to mental health services for children and youth with neurodevelopmental conditions](#) April 2023.

¹³ [Autism Month Celebrates Improved Services for Children](#)

¹⁴ [New Exemptions for Caregivers of Disabled Children](#)

¹⁵ [Province seeks public input on services for children, youth with support needs](#)
[| BC Gov News](#)

¹⁶ Pseudonyms have been used for Charlie and his family members to protect their privacy

¹⁷ [BC Gov News](#)

¹⁸ [Alone and Afraid: Lessons Learned from the Ordeal of a Child with Special Needs and His Family RCY Annual Review Year 4](#) (rcybc.ca)

¹⁹ [BC Gov News](#)

²⁰ [Children and youth with support needs – Family support services – Province of British Columbia](#)

²¹ Respite services offer families rest and relief, provided through either respite support coordinated through an agency, known as Agency Coordinated Respite, or through funding provided directly to families to purchase the respite services that best meet their needs, known as Direct Funded Respite. Respite funding requests may not be available immediately and families may be prioritized for service.

²² More information on this survey can be found in the RCY report [No Time to Wait A review of MCFD's child welfare workforce Part One](#) July 2024.

²³ [BC Gov News](#)

²⁴ Community Services are provided by contracted community agencies and offer direct support and intervention to young children and their families: Early Intervention Therapy (EIT) provides community-based physiotherapy (PT), occupational therapy (OT), and speech-language pathology (SLP) The age range for this program is birth to school entry.

Infant Development Program (IDP) and Aboriginal IDP (AIDP) help families develop tools and access resources to promote optimal child development.

School-Aged Therapy (SAT) provides OT and PT services to school aged children with support needs. This program is jointly funded and administered by MCFD and MECC in partnership with boards education, independent school authorities, and Ministry Service Delivery Areas.

Support Child Development (SCD) and Aboriginal SCD (ASCD) enable children with support needs to participate in inclusive child care. FASD Key Worker Parent Support Program provides support to families of children and youth under age 19 with Fetal Alcohol Spectrum Disorder (FASD) and similar neurodevelopmental conditions. Key Workers assist families in understanding FASD by providing education and information specific to the needs of the child and family.

²⁵ The [Early Intervention Therapy \(EIT\) Program](#) provides community-based occupational therapy, physiotherapy, speech-language pathology and support services for eligible children and their families. These services support optimal growth and development for children who have – or who are at risk of – developmental delay or disability. These services are provided from birth up to school entry.

²⁶ [BC Gov News](#)

²⁷ RCY analyzed the CYSN Financial Modelling Draft Final Report dated January 11, 2021 submitted to MCFD by Deetken Insight. The purpose of this report “was to develop an analytical model to understand the financial and service delivery implications of moving to the Future State Service Delivery Framework” (p. 4). In this case, the “Future State Service Delivery Framework” was the new MCFD CYSN Framework model announced on October 25, 2021 that proposed a system of services based on need, not diagnosis, and included the implementation of 45+ Family Connections Centres (FCCs) across the province and the discontinuation of the autism individualized funding programs. The Deetken report found that the cost to deliver the Target Future State model and serve 15,000 more children would be \$3 million LESS than the cost to deliver the Current State model. To do this, the Deetken analysis proposed that “service intensity” would need to be reduced from 100 percent to 90 percent. Reducing service intensity can negatively impact service quality. Specifically, the report proposed that this reduction would primarily affect children accessing autism individualized funding programs. By their estimates, in 2031, 40 percent of autistic children would receive the same level of access to services as now, and approximately 60 percent would receive less access to services in the new system.

²⁸ [Press Release \(nationbuilder.com\)](#)

²⁹ Calculation: According to the [BC Population Estimates & Projections \(shinyapps.io\)](#), the 2023 population of children aged 18 and under in the FCC regions (Central Okanagan, Haida Gwaii, Prince Rupert, Terrace, Kitimat, Nisga’a, Smithers, and Stikine) is 58,216. The total B.C. population of children aged 18 and under is 972, 582. Therefore, the percentage of children aged 18 and under in the FCC regions is six percent ($58,216/972,582 = 0.059$).

³⁰ The Spring 2025 date was stated during the MCFD “Services for Children and Youth with Support Needs: Emergent Themes and Concepts from Ongoing Engagement and Research” Webinar on September 5, 2024.

³¹ It is important to note that these eight years also included challenges faced by all government services to provide programs through the COVID-19 pandemic.

³² [Budget 2023 Increases Financial Supports for Foster Families | BC Foster Parents Association](#)

³³ Through the administrative fairness process, MCFD indicated that privacy and information sharing laws can create limitations in sharing information across government, ministries and service providers. These limitations speak directly to Collective Responsibility #4 in *Don't Look Away* that focuses on accountability including the creation of tools and systems that allow us to know who we need to serve, what they need, how best to serve them, what is effective and how we can collaborate and share information across systems.

³⁴ Percentage was calculated using the following: MCFD provided RCY with data on the number of children and youth (age 0 to 19) who at any time were/ are eligible for Children and Youth with Support Needs programs and/or community-based services, the Fetal Alcohol Spectrum Disorder (FASD) Key Worker & Parent Support Program, Autism Funding Programs, and/or the At Home Program who are in care or out of care by legal status as of Dec 31 each year from 2019-2023. This data was compared the total number of children and youth in care each December from 2019 to 2023 retrieved from the Corporate Data Warehouse on July 9, 2024.

³⁵ [Schwartz C, Barican J, Yung D, Cullen A, Gray-Grant D, & Waddell C. \(2023\). Addressing mental health needs for children with neurodevelopmental conditions. Vancouver, BC: Children's Health Policy Centre, Faculty of Health Sciences, Simon Fraser University.](#)

³⁶ Heslon, K., Hanson, J. H., & Ogourtsova, T. (2024). Mental health in children with disabilities and their families: red flags, services' impact, facilitators, barriers, and proposed solutions. *Frontiers in rehabilitation sciences*, 5, 1347412. <https://doi.org/10.3389/fresc.2024.1347412>

³⁷ See end note 22.

³⁸ RCY Reports: [Update: System of Services for Children and Youth with Special Needs](#) September 2010; [Isolated and Invisible: When Children with Special Needs are Seen but Not Seen; Still Waiting First-hand Experiences with Youth Mental Health Services in B.C.](#) April 2013; [Missing Pieces Joshua's Story](#) October 2017; [Alone and Afraid Lessons learned from the ordeal of a child with special needs and his family](#) December 2018; [Left Out: Children and youth with special needs in the pandemic](#) December 2020; [Excluded: Increasing Understanding, Support and Inclusion for Children with FASD and their Families](#) April 2021; [Still Left Out: Children and youth with disabilities in B.C.](#) November 2023; [Key Components of Effective Service Delivery for Children and Youth with Support Needs and Their Families: A Research Review and Analysis](#) February 2023; and [Toward Inclusion: The need to improve access to mental health services for children and youth with neurodevelopmental conditions](#) April 2023.

³⁹ Source: 2024 ADM Hospital and Provincial Services Estimates Materials for 2024
“As of January 15, 2024, the median wait time for an autism diagnostic assessment by the BC Autism Assessment Network through the MoH was 91 weeks (~ 1 year, 8 months) from date of referral to first appointment. However, depending on the health authority this wait time can range from 66 weeks (~1 year, 3 months) to over 119 weeks (2 year, 3 months).” Please note these numbers are not comparable to numbers published by RCY in the past regarding wait times due to changes in the way that they are calculated. Previously, wait times were measured based on the time from referral to diagnosis/case closed rather than the current measurement of referral to first appointment.

⁴⁰ Source: 2024 ADM Hospital and Provincial Services Estimates Materials for 2024
“As of January 15, 2024 depending on the health authority the median wait time for a diagnostic assessment by the Complex Developmental Behavioural Conditions (CDBC) program through the MoH can range from 12 weeks (~3 months) to 69 weeks (~1 year, 4 months).”

Please note these numbers are not comparable to numbers published by RCY in the past regarding wait times due to changes in the way that they are calculated. Previously, wait times were measured based on the time from referral to diagnosis/case closed rather than the current measurement of referral to first appointment.

⁴¹ For example, children must receive a formal diagnosis of autism to be eligible to receive funding through the Under Age 6 Autism Program. In addition, the At Home Program, requires a doctor referral and an assessment by a nurse. Access to a doctor and/or a nurse will vary depending upon the availability across the province.

⁴² This child also lives in a rural and remote community in B.C. with minimal access to a family physician and/or a pediatrician.

⁴³ [Exclusion Tracker Report 2022-23](#)

Exclusions are reported by parents/caregivers through BCEd Access' online exclusion tracker. The 2018-19 report revealed findings from 492 respondents documenting an estimated 3,610 incidents of exclusion. The 2020/21 report had 193 respondents and an estimated 4,376 incidents of exclusion. The 2022/23 report revealed findings from 406 respondents documenting an estimated 5,973 incidents of exclusion.

⁴⁴ [Exclusion of students from school – Office of the Ombudsperson](#)

⁴⁵ Families were asked – “In addition to the services and supports that you are receiving, what OUT OF SCHOOL services and supports do you or your child/ren NEED right now?” 38 percent chose: Mental health supports for me and/or members of my caregiving circle (e.g., relatives, siblings, others living in your home, etc.).

⁴⁶ Families were asked the following – “Do you ever use your own funds to pay for assessment, therapy, equipment, transportation that are related directly to your child’s service and support needs?” and “On average, how much do you estimate to spend each month on services and supports related to your child’s disability that are not covered through government funding?” Some examples of what families

reported they had to pay out-of-pocket for included: Support Workers/Behaviour Interventionists; Psycho-Educational Assessments; Autism Assessments; Therapies (Physiotherapy, Occupational Therapy, Speech Therapy); Counselling; Medically necessary medications; Peditasure; etc.

⁴⁷ [A Framework For Action \(gov.bc.ca\)](https://www2.gov.bc.ca/gov/content/child/youth/families/autism/framework)

⁴⁸ [OPINION-EDITORIAL: Making a difference for individuals with disabilities in B.C. | BC Gov News](#)

December 1, 2012

⁴⁹ [B.C. is embracing ability, encouraging inclusion | BC Gov News](#) March 11, 2013

⁵⁰ [Accessible British Columbia Act \(gov.bc.ca\)](https://www2.gov.bc.ca/gov/content/child/youth/families/autism/framework)

⁵¹ Through the administrative fairness process, government provided the following excerpt from the 2022 CYSN Framework as an example of cross-government coordination: “In 2019, we heard from children, youth, families, Indigenous Peoples and leaders, service providers, physicians, cross-government partners, and other individuals who shared their stories, insights, and lived experiences...this input shaped the current Service Framework that is guiding the development of policy, services, and supports for children and youth and their families.” However, this excerpt provided no definition of “cross-government” partners, and it does not indicate how or what type of coordination of services with cross-government partners has occurred beyond sharing “their stories, insights, and lived experiences.”

⁵² The CYSN services that were in scope for this analysis were as follows: CYSN community-based services, including the Infant Development Program (IDP), Aboriginal IDP, Supported Child Development (SCD), Aboriginal SCD, Early Intervention Therapies (EIT), FASD Key Worker Program, and School Age Therapies (SAT); the At Home Program that provides medical benefits and respite to those who qualify; the Autism Individualized Funding Programs; CYSN residential services; and CYSN Family Support Services, including CYSN worker supports, respite and other professional supports, behavioural supports, and homemaker supports.

⁵³ See end note 22.

⁵⁴ News Release 2008 CFD0037-001191, July 31, 2008

⁵⁵ [Changes to Autism Programs Increase Funding and Equity](#)

⁵⁶ [Number of families waiting for respite funding cut in half | BC Gov News](#)

⁵⁷ The respite analysis calculated both the respite rate increase and the increase in the number of children receiving support. Like wage lifts, the respite rate increases did not increase the number of children receiving support. However, the rest of the change in spending in respite was captured as ‘growth’ in the analysis and was not grouped in with wage mandates.

⁵⁸ In the administrative fairness process, MCFD advised that, “increases to funding caps within Autism and Medical Benefits were also included in these budget increases (e.g., increased rate caps for therapists).” The impact of these rate cap increases were not yet reflected in the financial data that RCY received as they were implemented in April 2023 and we received data only up until that date.

⁵⁹ In British Columbia, a Government Estimates Note is a package of information prepared by each ministry to support their minister during budget debates. It contains a detailed breakdown of proposed spending by ministries and government agencies for the coming fiscal year. RCY receives Estimates Notes through section 10, Right to Information, of the *Representative for Children and Youth Act*. MCFD estimates notes referenced in this issue spotlight were received between June and August of each year.

⁶⁰ See Footnote #1

⁶¹ See Appendix A for analysis

⁶² *Alone and Afraid* Recommendation #1 States: “That MCFD undertake a comprehensive assessment of the actual need for CYSN services across B.C. and the capacity of the current system to meet those needs. This assessment to examine funding, staffing levels and workloads, program delivery and wait times. Findings to be used to inform comprehensive service improvements so all eligible children with special needs and their families receive culturally respectful, appropriate and timely services and supports. MCFD to complete the comprehensive assessment and plan by the fall of 2019, seek necessary funding enhancements and begin implementation of changes by April 2020.”

⁶³ Through the administrative fairness process, MCFD shared that they have begun enhancements to their integrated case management (ICM) system in the FCC pilot regions with a goal to improve the ministry’s ability to capture reliable information about programs and services, dates, duration that have historically been through contracted service providers. However, the evaluation of the FCC pilot programs has not been completed. Therefore, it remains unclear if the ICM enhancements will result in improvements in data collection.

⁶⁴ Elder Shane Pointe, Coast Salish Knowledge Keeper, B.C. Disability Summit, Vancouver B.C., June 19, 2024.

⁶⁵ RCY CYSN Check-In Survey

⁶⁶ MCFD calculated this percentage as follows: MCFD starts with MECC’s special need enrollment counts and then they remove the gifted counts, bringing the 12.7 percent estimate down to 12.1 percent. They then adjust for prevalence of special needs in under school age children 2.7 percent (Source: Canadian Health Survey on Children and Youth 2019 – Stats Can) and prevalence of special needs in children ages 5-18 not in school – 1.3 percent (Source: The Daily — Canadian Survey on Disability, 2017) to arrive at 9.7 percent.

⁶⁷ Source: [Breaking down barriers: A new way to measure progress for Canadians with disabilities – Statistics Canada](https://www150.statcan.gc.ca/n1/pub/82-625-x/2019001/article/00001-eng.htm) (statcan.gc.ca)

⁶⁸ Source: MECC Estimates e-binder, March 27 2023

⁶⁹ Ministry of Education and Child Care Estimates Notes (2023).

“Diverse need” designation includes the following inclusive education categories: physically dependent, deafblind, moderate to profound intellectual disability, physical disability or chronic health impairment, visual impairment, deaf or hard of hearing, autism spectrum disorder, intensive behavioural interventions or serious mental illness, mild intellectual disability, gifted, learning disability and moderate behaviour support/mental illness.

⁷⁰ The calculation to estimate the number of children receiving services each year was done as follows. We used the baseline of 30,000 for the number of children and youth with disabilities receiving services taken from the MCFD 2011 Estimates note. Then, to estimate how many new children were served each year, we first estimated the amount of spending growth per year (excluding increases in collective agreement wage lifts and respite rate increases) that was left for new services to more children in a sub-set of the CYSN funding programs (foundational, SCD, respite, at home, FASD and other family supports). Specifically excluded is spending related to the Autism Funding Program, Residential Services, and Program Delivery (line staffing). We then divided this spending growth by the previous year's spending to get a percentage change in spending growth and made the assumption that this growth would be allocated to new services for more children. Finally, we took that percentage growth and multiplied it by the clients served in the previous year to get the total new number of children served in each subsequent year. For example, in 2011, there were 30,000 children served. The spending growth percentage for new services in 2012 was 0.15 percent. Therefore, $30,000 \times 1.15$ percent = 30,045 children – or 45 more children served. This same calculation was repeated for each year, reflecting the specific rate of growth experienced in that year. The resulting number of children who likely received services was subtracted from the total population of children and youth with disabilities to reveal the number and percentage of children who went unserved/did not receive CYSN services in each of those years. Through the administrative fairness process, MCFD provided this additional information: "It is possible that service utilization increased alongside funding increases, i.e., existing CYSN children used more services (Autism Funding, At Home Program, Family Support Services). This would reflect more services for the same children. This would be separate from/in addition to new services for new children.

⁷¹ It is possible that some children and youth may be receiving services from other government funded programs such as mental health services. However, statistics Canada reveals that mental health conditions co-occur with other disability diagnoses and so, children receiving mental health services cannot be considered unique cases. (e.g., Stats Can (2017) – [4 in 5 Canadians with a mental health-related disability also have at least one other type of disability. The lack of disaggregated data or a personal identification number makes it impossible to know if these children are receiving services from some other facet of the system.](#)

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