

# Still Left Out: Children and youth with disabilities in B.C.

November 2023



REPRESENTATIVE FOR  
CHILDREN AND YOUTH





Nov. 9, 2023

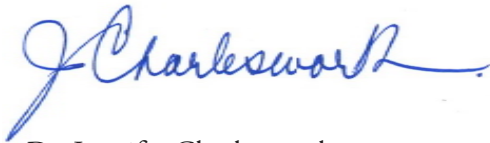
The Honourable Raj Chouhan  
Speaker of the Legislative Assembly  
Suite 207, Parliament Buildings  
Victoria, B.C., V8V 1X4

Dear Mr. Speaker,

I have the honour of submitting, *Still Left Out: Children and youth with disabilities in B.C.*, 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,



Dr. Jennifer Charlesworth  
Representative for Children and Youth

pc: Ms. Kate Ryan-Lloyd  
Clerk of the Legislative Assembly  
Jinny Sims, MLA  
Chair, Select Standing Committee on Children and Youth  
Mike Bernier, MLA  
Deputy Chair, Select Standing Committee on Children and Youth

# Acknowledgments

The Representative would like to acknowledge with gratitude the many families who shared their stories and experiences with us for this report and those families who completed our survey despite incredibly busy lives.

She would also like to acknowledge the Community Partners who generously shared their time and insights with us:

Aboriginal Infant Development Program

Aboriginal Supported Child Development

ACT-BC

BC Association for Child Development and Intervention

BC Complex Kids Society

BCEdAccess Society

Family Support Institute

First Call Child and Youth Advocacy Society

Inclusion BC

Inspire Kids FASD Support Society of BC

Union of British Columbia Indian Chiefs

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## **Territorial Acknowledgment**

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

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

## Executive Summary

It's been nearly three years since the Representative for Children and Youth (RCY) released a report examining how families of young people with disabilities<sup>1</sup> were coping in the midst of a global pandemic.

That report, *Left Out*,<sup>2</sup> revealed that while COVID-19 was making life more difficult for these children and families, they had in fact been struggling long before the pandemic hit – to find supports and services in a publicly funded system that far too often didn't meet their needs.

Fast forward three years and what has changed? That's what the Representative sought to determine in this report, as RCY re-engaged with the 10 B.C. families whose stories were told in *Left Out*.

The answer, unfortunately, is not enough. Families of children with disabilities are still struggling with a system of supports and services that is under-resourced, filled with closed doors and lengthy wait lists for assessments and treatment, cumbersome to navigate and difficult for parents to understand.

In compiling this report, RCY also followed up with four families from its 2021 *Excluded*<sup>3</sup> report, which examined the inequities in supports and services for young people with fetal alcohol spectrum disorder (FASD). In addition, RCY conducted an online survey of more than 1,000 other B.C. families of children and youth with disabilities.

The Representative acknowledges that the Ministry of Children and Family Development (MCFD) is in the midst of re-imagining its Children and Youth with Support Needs framework, but that much-delayed process is already nearly six-years-old and still at least a year-and-a-half away from any resolution. For children who are waiting for services, that period represents a large chunk of their childhood.

In November 2022, when the provincial government announced it was pausing its framework rollout to undertake an engagement process co-designed by First Nations leadership and leaders from the disability community, Premier David Eby stated: “Every child in B.C. should have the supports they need to thrive.”

This report shows that is still not the case. The Premier and Minister of Children and Family Development also committed at the time to making “new investments in the interim, as the new system is being developed to support children with disabilities and support needs that are currently underserved, including fetal alcohol spectrum disorders (known as FASD), Down syndrome and other neuro-cognitive developmental disabilities.”

However, the “under-served” are not faring much better since that announcement, either. Children with FASD, for example, are still ineligible for services that those with some other diagnoses – such as autism spectrum disorder – receive. The same goes for children with Down syndrome. In fact, more than 34 per cent of survey respondents told RCY that they have children with disabilities who are currently ineligible for any support.

<sup>1</sup> RCY has chosen to use this term rather than “children with special needs/support needs.” When referring to the specific CYSN program for these children and youth, this report refers to the program name, Children and Youth with Support Needs.

<sup>2</sup> Published Dec. 3, 2020. Full report at this link: <https://rcybc.ca/reports-and-publications/cysn-report/>

<sup>3</sup> Published April 15, 2021. Full report at this link: <https://rcybc.ca/reports-and-publications/excluded/>



The result, unfortunately, is that hope is waning. Almost three-quarters of the more than 1,000 parents and caregivers of children and youth with disabilities who responded to RCY's survey – from every region in B.C. – reported feeling “no confidence” or “minimal confidence” that their child would receive the services they need, whether in or out of school, within the next one to three years.

The Representative knows that there is a fine line between a manageable life and an overwhelmingly difficult one for parents of children and youth with disabilities. Parent, caregiver, tutor, case manager, medical adviser, advocate – they will need to be all that and more over the lifetime of their child.

But as RCY routinely hears from such families, their children's disabilities are not the primary stressor in their lives. They're being worn down, overworked and pushed to the brink of their coping abilities by the system that is supposed to be helping them. RCY Advocates working alongside families and caregivers continually engage with government and CYSN staff want to be helpful to families, but currently have limited or no options to offer.

The result: Families are still being left to wait – not just weeks or months, but years. “This is urgent,” one mom told RCY. “We've been ignored for far too long.”

What families told RCY is that they continue to struggle under a piecemeal, uncertain and profoundly inadequate system of services and supports. And those are the families who are able to access services. RCY estimates that as many as 80,000<sup>4</sup> B.C. children and youth with disabilities are currently not receiving any support.

B.C. children and youth with disabilities account for a significant number of the critical injuries and deaths that RCY reviews in any given year. In the period April 1, 2021 through March 31, 2023, this population of children and youth<sup>5</sup> accounted for 35 per cent of children and youth impacted by a critical injury or death reviewed by RCY.<sup>6</sup> They made up 46 per cent of deaths and, of the injuries experienced, 58 per cent were attributed to this population.

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<sup>4</sup> RCY acknowledges that this number may be an under-estimation. For example, children and youth with ADHD may not be included in this data set as ADHD does not have its own specific inclusive education designation.

<sup>5</sup> In the context of RCY data children and youth with disabilities refers to a child or youth having a CYSN reviewable service area or a complex developmental behavioural condition (CDBC) attributed to their reportable circumstances (received by RCY) at some point before or during the reporting period (April 1, 2021 to March 31, 2023). A child or youth would have CYSN coded if they are currently receiving CYSN services, are wait-listed, or in rare cases where they are the sibling of a child/youth whose family is receiving CYSN funds and an in-mandate emotional harm record was received. There is a possibility this is the only reportable RCY receives for these youth (the siblings of those with CYSN services), however they are coded as having CYSN reviewable service area due to the familial-funding nature of CYSN. A child or youth would be classified as having a CDBC if they have significant difficulties in multiple areas of functioning such as learning and development, mental health, and behaviour, adaptive and social functioning. This can include a formal diagnosis or suspicion of neurodevelopmental disorders such as ADHD or FASD.

<sup>6</sup> Children and youth identified in this cohort are limited to children and youth who had at least one reviewable service area attributed to their reportable circumstance received by the RCY before or during April 1, 2021 to March 31, 2023 and include both in mandate and out of mandate injuries and deaths. Reviewable services are defined in the *RCY Act* as those provided under the *Child, Family and Community Service Act* and the *Youth Justice Act*; publicly funded mental health services for children, addiction services for children or another government service, as directed by the Lieutenant Governor in Council.



The number of these children and youth who were in government care at the time of their critical injury or death, 80 per cent, is almost double that of their peers without disability classifications at 47 per cent. Forty-three per cent had mental health files. Indigenous children and youth made up the majority of this group in the 2021 to 2023 time period, with 43 per cent First Nations and 10 per cent Métis.

“Many parents, including me, are overwhelmed by the non-stop care needs of their child with special needs. Respite is helpful but is still a small drop in the very deep bucket of need,” wrote one survey respondent. “Burnout is very, very real. The system is broken and I am too tired to figure out how to fix it.”

Families speak of systems that seem like they’re set up to reject their requests and make them fight for every dollar of support. They are up against processes that feel deliberate in denying or complicating their ability to access the supports their children need. They are exhausted – worn out from their multiple roles as parents, caregivers, case managers, advocacy experts, form-fillers, systems strategists and breadwinners.

More than half of the survey respondents either “strongly” or “somewhat” disagree that the supports their child currently receives are adequate in meeting their needs.

“The system is marginalizing families,” says one mom. “Our kids are not the challenge – the challenge is the system. Why not try just giving us the right support and see how that goes?”

This report presents the stories of 14 families, including 25 children, and RCY’s survey results organized into four broad age groups, which document how families are experiencing B.C.’s systems of support as their children transition from birth to young adulthood. It begins with the preschool years, then looks at early school years; later school years; and early adulthood. The report concludes with a Call to Action.

The Representative is grateful for the participation of the children and families from *Left Out* and *Excluded* in this report. RCY also appreciates the overwhelming response to the survey in what was a relatively short timeframe. Finally, the Representative is grateful for the input provided by the ad hoc advisory group of provincial organizations whose advocacy work puts them on the front lines of these issues and whose knowledge informed both *Left Out* and this report.

It’s clear that the children of B.C. and their families must not be left to wait any longer. Short-term relief promised a year ago must be delivered now and CYSN framework revisions must be expedited.

As First Nations children’s advocate Cindy Blackstock states, “Children only get one childhood. Fix it today.”

## Context

### CYSN plan in limbo

In 2018, government began a process of consultations across the province to inform the development of a new CYSN framework. Three years later, plans for a new system that families could access based on a child's needs were announced.

That news brought much hope to the tens of thousands of B.C. families whose children are currently not eligible for any CYSN services due to not having a diagnosis, or who have a diagnosis that isn't eligible under current guidelines (Down syndrome, FASD, attention deficit disorder and more).

The reform envisaged the development of between 40 and 45 community service hubs known as Family Connections Centres (FCCs), which would provide one-stop access to CYSN services, navigators to help families find what they need and satellite services in remote communities.

The reform was welcomed by families who are currently receiving no services, but also sparked fear and confusion among families who have fought hard for the services they have. They were concerned about losing their existing trusted service providers and losing agency around how support dollars are used for their child.

Other families raised concerns about the funding structure associated with the changes and questioned if it would truly meet the needs of all children and youth with disabilities across B.C. or just create further wait lists for services. This fear is certainly valid if MCFD proceeds with expansion plans for a mere 8,300 children and youth using narrowly defined eligibility criteria, when the actual number of children and youth with disabilities is as much as 10 times higher.<sup>7</sup>

The public pushback led to the planned reform of CYSN being put on hold a year ago, after incoming Premier David Eby communicated to the public that more consultation was needed.

In the months since that announcement, government has provided funds to disability-based and Indigenous organizations to expand on engagement and consultation. This is an important step. However, this engagement plan will not conclude until January 2025.

In the meantime, pilots for the new FCCs that are intended to serve children and youth based on their needs are proceeding in four regions, as contracts were already being negotiated prior to the premier's announcement. But as of the date of this report, only one of the four centres, in the Okanagan, has been substantially implemented. The remaining three in Prince Rupert/Haida Gwaii, Smithers/North Coast Bulkley Nechako and Terrace/Kitimat will not be substantially operational until the end of 2023 or early 2024.

Results of the evaluation of these sites will not be available until after January 2025.

In other words, it appears that a new CYSN system will not be unveiled until months into 2025 at the earliest. Families with children and youth whose diagnoses deem them "eligible" for services will still have to rely on a broken system for the foreseeable future. Even more troubling, tens of thousands of families of children and youth with disabilities that aren't currently eligible may continue to be left out.

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<sup>7</sup> Numbers are based on RCY's estimation of prevalence numbers that will be discussed further in the report.

“There has been a complete lack of communication from the government since Premier Eby reversed the decision on switching to a hub system,” said one survey respondent. “Not only that, but there are communities that are engaging in the hub pilot and there has been no discussion on this, and how things are going. The government needs to be more transparent with what they are doing and planning. If they don’t, many children and their families will be negatively impacted.”

It is notable that only 10 per cent of families surveyed said they were “adequately” or “very informed” of the potential changes in the CYSN service system. Eighty-two per cent said that they were “not at all” or “only somewhat” informed of the changes.

Since the original consultations in 2018, little has changed for most B.C. families of children and youth with disabilities. Eighty-five per cent of RCY survey respondents told us services for their child have either stayed the same or worsened in the last three years.

We acknowledge some recent bright spots, however: government has increased funding to equipment allowances, and the amount it reimburses for therapies such as physio, occupational therapy and speech/language services. Several policy changes that were initiated during the global pandemic to provide more flexibility and more support to children and youth with support needs and their families have been sustained (e.g., policy that supports flexible use of direct funded respite).

These changes have reduced and in some cases eliminated significant top-up amounts that families have been paying out of their own pockets for their children’s specialized equipment needs and therapy appointments.

But for the majority of CYSN families in B.C., what we heard in the 2020 *Left Out* report and the 2021 *Excluded* reports still rings true in 2023. They still struggle to get the services they need. This follow-up report sadly demonstrates that far too many of the province’s children and youth with disabilities are still left out, and still not receiving the supports they need.

They are still waiting for assessments to accurately identify their needs. Still waiting to access therapies. Still waiting to be supported in the school system and for mental health services. Their families are still waiting for respite. Still navigating through the service-system maze on their own. Almost 80 per cent of our survey respondents said that they struggle to navigate the system. Still challenged to balance their lives between ensuring their children receive the care they require, paying the mortgage, household bills and caring for themselves.

“The constant fight or flight that caregivers are in is alarming. We need to start supporting families financially and emotionally before burnout happens,” wrote one survey respondent. “Families are stretched to their limit and help is never close by. It’s always 45 forms and one year away. Since December 2021 I have had to pay over \$30,000 in medication, transportation upgrades and home upgrades to keep my child safe.”

Some families continue having to contemplate whether to place their child in the care of government, just to get the services and supports that their child needs and deserves. Of the 68 families in our survey who have placed their child in care under a special needs or voluntary care agreement, 21 per cent said they made that decision solely to get services that the child could not get if they remained in their own home. Among the more than 1,000 families responding to RCY’s survey, 14 per cent said they have considered doing the same.

## Context

That families would ever have to consider such a thing just to get essential services speaks to how critical the lack of adequate supports has become.

The current service system remains diagnosis-based. It was clear when interviewing families for this report that many are still outside looking in at a system of support that inexplicably privileges particular diagnoses. This form of discriminatory privileging results in unconscionable inequities and divides families and community.

For example, the current system includes the Autism Individualized Funding program (AIF), available only to children and youth with a diagnosis of autism. As one parent whose child has significant needs but no autism diagnosis notes, this diagnosis-based criteria has essentially “paved one road in” to CYSN services.

“The school, the daycare, the child development centre – they all drive families to autism because that’s the only paved road to help in B.C.,” said the mom. “But then you drive down that road and everyone’s delivering it in the same way, even when every child’s needs are different.”

As other stories in this report highlight, however, even that lone paved road for autism services is far from being paved with gold. Families who are able to access AIF and other existing programs still face many barriers, and the situation appears to be getting worse across CYSN services. Forty-six per cent of the families surveyed by RCY said access to supports and services for their child had worsened in the last three years.

“Government gives you the money, but they make you work so hard for it,” says one mother of twin boys with autism diagnoses. “That my boys have autism is not my life challenge, it’s all the other stuff that goes on.”

The families that RCY heard from in communities large and small – families who have already surmounted the challenges of getting a diagnosis and qualifying for CYSN services – report that essential health and social services their children need are hard to find, even harder to access and are rarely sufficient.

“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,” wrote one survey respondent. “This is not sustainable. We want our child’s medical needs taken care of so we can be parents. We are not nurses.”

Years-long wait lists in some regions for critically important services such as the Supported Child Development Program (SCDP) effectively mean that no such service exists for many families. Meanwhile, families eligible for respite supports report not being able to find anyone to hire. Even the contracted agencies in their communities that are supposed to be supplying families like theirs with respite are not able to find consistent workers.

Many families told RCY that they had to make life-changing decisions to privately fund services their child needs to give them their best chance to succeed. That can mean a parent quitting their job or a family going into debt, or having to make the tough choice of moving to a location where more services are available, but the cost of living is higher and the family now finds themselves far away from their natural support systems. Some are using up their retirement savings.

“I’ve got a credit card, my husband works and I’m on disability. But there are days when I think, how can I buy these groceries?” said one woman whose family had to relocate to the Lower Mainland from the north to find their son more services.

## Inequities for families

The current system's requirement for diagnosis and/or professional assessment to establish eligibility for publicly funded services was meant to ensure the best use of publicly funded resources. However, it has proven highly problematic and the Representative recognizes and supports the provincial government's plans to move away from diagnosis as a gatekeeper to services.

We have found that B.C. families' experiences of being able to access services for children and youth with disabilities vary tremendously and in profoundly unfair ways.

Two children with comparable needs receive vastly different levels of support in B.C. solely based on what diagnosis they have. Inequity has intensified in recent years, with wait times for assessment for an autism diagnosis at 81 weeks, meaning that some families are waiting significantly longer through the BC Autism Assessment Network and more than a year for a diagnostic assessment through the Complex Developmental Behavioural Conditions program,<sup>8,9</sup> pushing some families into the private sector for services while other families do without.

This difference is not because one condition is more debilitating, impactful or costly than another, but because a particular diagnosis has a more robust political lobby than others. In the case of autism supports, a history of lawsuits hard-fought by desperate parents played a role in political decision-making around funding.

"I get it. Parents with kids with attention deficit disorder, with Down syndrome – they want support too. Those parents look at us as greedy, selfish," the mom of a boy with autism told RCY. "But look at the history here, how autism parents had to fight, even launch a court case. It's parent pitted against parent. Every parent deserves support, and should not have to fight with each other to get it."

Families interviewed by RCY spoke of systems that too often view their children's needs as temporary, when in reality they will have their disability for a lifetime and may always need some support. Families say they are having to repeatedly emphasize their child's deficits to try to access services as their child ages into new systems and new rules – or even just to hold onto the ones they have. Whether a family can acquire essential services for their child too often comes down to how skilled a parent is at advocacy and their capacity to take on this level of advocacy within and across systems.

Children and youth do not exist in silos. They live in community, accessing municipal services; health services; education services; recreational services; transition to adult services; and more. While the focus has been on MCFD and its CYSN framework, children with disabilities have rights and needs across multiple government ministries and agencies, including Health, Education and Child Care, Social Development and Poverty Reduction, Housing, and Community Living BC (CLBC).

Families report having to constantly re-tell their story across these systems, many of which have different rules for access.

<sup>8</sup> Information received by RCY from the Ministry of Health, July 7, 2023.

<sup>9</sup> Assessments for complex developmental conditions are intended for children and youth who have significant difficulties in multiple areas of function including those with known or suspected history of exposures to substances with neurodevelopmental effects.

## Context

Those families also do not exist in silos. They need to be supported with consistent and reliable child care. They need flexible employment opportunities, accessible housing and suitable transportation.

“I have needed a medical stress leave twice to urgently care for my son. We have lost income, but more importantly, our SANITY because we are so dependent on a Jenga set of precarious systems to patchwork-cover his needs,” wrote a survey respondent.

“I am not well. I am so tired I don’t think I will ever recover. Seeking dignity for my child’s existence has broken me, and shattered my faith in government and our society,” wrote another survey respondent.

With no underlying cross-ministry vision in B.C. for how to implement supports and services across systems, families feel that they are having to fight at every door for everything they get and must always be “the squeaky wheel.” They talked of how exhausting that is for them, and how impossible it must be for any family with fewer resources or advocacy skills than their own.

“What do we need the most? Not to have to fight for everything,” said one mother. “I have to explain over and over, get a letter from here, a letter from there. It wears us out. You spend all your time telling people the same story, and then only to have them say ‘Oh, sorry, we can’t help.’”

Even for children and youth with a clear and funded diagnosis that ticks all the boxes for support under the current system, there’s a long list of other factors that affects a family’s actual ability to access services. They include, among other things:

- the type of disability a child has and how it impacts their functioning
- where the family lives
- whether the family is a foster, adoptive or biological family
- whether someone in the family has the time and talent for advocacy to be a “squeaky wheel”
- if they are Indigenous
- whether a family can afford to top up partially funded therapy services or carry the costs of their child’s services while waiting for reimbursement
- age (and even month of birth) of the child or youth.

“So disappointed in our system!” wrote a survey respondent. “Our children are not being set up to thrive and be successful in our province.”



## Who's not here

RCY recognizes the limitations of a report in which the stories being shared come only from the families with sufficient energy and personal resources to be visible in their advocacy, and who can take the time for interviews and follow-up. So many other family stories remain untold.

In B.C., it isn't known how many families are raising children and youth with disabilities. There is little baseline information that details who these families are, where they live, what they need and how they are managing in their daily lives.

The data that the Representative has been able to estimate are the number of children and youth receiving services and supports within the current CYSN system (which includes AIF,<sup>10</sup> the At Home Program<sup>11</sup> and Family Support Services<sup>12</sup> and Nursing Support Services<sup>13</sup>). Using approximate CYSN caseload numbers of children accessing CYSN services provided by MCFD, which is only those children and youth with a diagnosis that fits within current CYSN criteria, it is estimated that there are currently 35,000 children and youth being served.

But little data exists on the children and youth with disabilities who are not being served because they don't have an eligible diagnosis. To better understand the actual level of need, RCY examined existing Ministry of Education and Child Care data along with B.C. population statistics to get an estimate of population prevalence.

What those calculations identify is not only that there are tens of thousands of children and youth going unserved within the current system, but that the government also significantly underestimated the number of children and youth who need support and services when the new CYSN framework was announced in October 2021.

<sup>10</sup> The Autism Funding Program provides assistance to families with purchasing eligible intervention services for children under the age of 19 who have been diagnosed with autism spectrum disorder. Families of eligible children under the ages of 6 to 18 may receive up to \$22,000 of annual funding and families of eligible children aged 6-18 may receive up to \$6,000 of annual funding, with funding discontinued at the end of the month of the youth's 19<sup>th</sup> birthday.

<sup>11</sup> The At Home Program provides medical and/or respite benefits to children and youth who are assessed as dependent in at least three of four areas of daily living (washing, dressing, toileting and eating.) Medical benefits are available to children and youth ages 0 to 18 and include access to medical equipment, supplies and services that are deemed medically necessary. Respite benefits are available to children and youth ages 0 to 19 and provide funding to families to purchase respite care. Based on eligibility one or both of the benefits are provided.

<sup>12</sup> Family Support Services is available to children and youth ages 0 to 19 who have been diagnosed with an intellectual disability, global developmental delay, autism spectrum disorder or who are eligible for the At Home Program. Families access Family Support Services through a CYSN social worker who interviews the family and determines the nature and level of family need. Services that may be available include respite, behavioural supports, support from a child and youth care worker, homemaker/home support services, parenting supports and professional supports.

<sup>13</sup> Nursing Support Services is available to children and youth in B.C. ages 0 to 19 who have complex health care needs. Community-based registered nurses provide medical support to eligible children and youth both in home and in the community. Services include direct care nursing respite, support for school staff to assist children and youth with their diabetes care and tube feeds and eligibility assessments for Ministry of Children and Family Development's At Home Program. A referral from a physician or nurse practitioner registered to practise in B.C. is required to access the program.

## Context

At that time, MCFD's expectation was that CYSN reforms would need to provide disability services to an additional 8,300 children and youth under a narrowly defined eligibility criteria in order to address the children and youth with disabilities in B.C. who weren't currently being served. However, RCY used a broader, more inclusive definition of disabilities and our estimates establish that MCFD's number is off by a factor of 10, and that there are actually as many as 80,000 additional B.C. children and youth who need support.

Here's how we calculated this gap:

We know that right now there are 86,615 children and youth in B.C. who have a "diverse need" designation.<sup>14,15</sup> We also know that according to the province's population statistics, the total number of school-age children and youth (ages five to 18) in B.C. in 2022 is estimated at 715,097. Using these two numbers, we can then calculate the percentage of the school-age population that have a diverse-need designation in B.C. schools (86,615 out of a total 715,097). The answer is 12 per cent.

Apply that percentage across the total population of B.C. children and youth ages birth to 18, and it emerges that a total 114,297 of them have a disability.

That means that the current system, serving approximately 35,000 children and youth, is at best serving fewer than half of those who need supports and services. More importantly, it means that any new CYSN framework would need to serve as many as 80,000 additional children and youth in order to meet actual needs.

The Representative strongly believes that MCFD has underestimated the number of B.C. children and youth requiring services in a needs-based model, by eight to 10 times. Rectifying that is critically important for families. They simply can't be left to wait even longer for government to realize down the line the impact of this major error in calculations.

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<sup>14</sup> Ministry of Education and Child Care Estimates Notes (2023).

<sup>15</sup> "Diverse need" designation includes 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.

## The dark at the end of the tunnel

This report presents the 14 family stories and our 2023 survey results organized into four broad age groups, which document how families are experiencing B.C.'s systems of support as their children transition from birth to young adulthood. The report begins with the preschool years, then looks at early school years, later school years, and early adulthood.

Virtually all children and youth qualifying for the province's CYSN services have lifelong disabilities and conditions. But their eligibility and access to publicly funded support services for their disabilities will change multiple times as they age and move through the various government systems, and then will end entirely for the majority of them when they turn 19. Even the federal Disability Tax Credit is not guaranteed once they reach adulthood, in many cases having to be reapplied for every few years depending on how the federal government opts to designate an individual's disability for tax purposes.

A system that supports children and youth with lifelong disabilities only to age 19 explains a great deal about why families fight so hard for supports while their children are young. For them, the end to vital services is always frighteningly in sight.

That 12 per cent of B.C. children and youth have disabilities means that 12 per cent of adults do, too. That's almost 528,000 adults in terms of the province's population. CLBC is the only real continuation of disability services and supports in B.C. past age 19. The *Community Living Authority Act* and Community Living Authority Regulation outline eligibility criteria of a subpopulation of individuals for CLBC services:

- Adults with a developmental disability, and
- Adults diagnosed with a fetal alcohol spectrum disorder or an Autism Spectrum Disorder, and who have significant limitations in adaptive functioning.

CLBC currently serves 27,340 people, with the past five-year average annual number of new registrants at 1,388.

That leaves potentially more than half a million British Columbians without any public body providing support specific to their disability. In many cases, they will continue to be dependent upon their families to address their needs.

This reality creates an understandably immense stress load on families of children and youth. They know all too well that adulthood will come soon enough for their child and the services won't be there. The families interviewed for this report told RCY that even in comparatively well-resourced periods when they have cobbled together the right supports for their child, they are in constant fear of how long it will last. Almost 80 per cent of survey respondents said their level of stress has either stayed the same or worsened in the past three years.

The weight is particularly heavy in the later teen years, when families are facing "the black hole of adulthood," as one parent termed it – the years when most services for children and youth have ended.

"Privately, I've had the ability to get things done that have changed my children's lives," says a mother of twins with severe physical disabilities. "But what about parents who can't? Before I had my kids, I would think, 'Why would anyone live anywhere but Canada?' Now I know. There's not free health care for everyone. There's not community access for all."

We begin with the preschool years and the story of Maria and her twins Adam and Jason.

## Maria's story

There will never be a year without challenges for parents of twin boys with significant disabilities. But if Maria, who lives with her boys in the Lower Mainland, can avoid another year like 2021, she'll count that as a life win.

"That was the worst year," recalls Maria. "I was having to work 40 hours a week all at night because I couldn't get the boys into daycare. Our family was the highest priority for it under government guidelines, but we still couldn't get it. We didn't get it until September 2022."

Twins Adam and Jason turned five this summer. Born at 27 weeks with a severe case of twin to twin transfusion syndrome, they experienced severe bilateral brain bleeds at birth. Both boys have cerebral palsy but Jason is more affected, unable to move on his own and requiring tube feeding.

Daycare for children like Adam and Jason requires the support of skilled aides at the daycare centre.

In theory, those aides are funded by B.C.'s Supported Child Development Program (SCDP). In reality, the annual funds allotted to each region can be quickly used up in regions with higher demand, like the populated Lower Mainland; in rural regions, the program can run into problems caused by a lack of skilled workers.

In Maria's case, the issue was funding. She did the legwork to find accessible daycares that would accept the boys – a major challenge on its own for families to figure out – only to discover that funds had run out in her region.

The family grew so frustrated with the situation that they tried to file complaints of discrimination with the B.C. Human Rights Tribunal and the Ombudsperson. But because daycares are considered private businesses, Maria was told they are not required to make accommodations.

That Maria was wait-listed for SCDP also meant the twins hadn't been refused service, human rights officials told her, they were simply unable to get it at that moment – or at any time in the previous four years, she adds.

"And maybe I could have taken that further," she acknowledges. "But I can't fight everything. Even when we finally got it in September last year, I think it was only because I was a squeaky wheel. If a B.C. child reaches age four without ever getting this funding, that's another tick on their priority list for getting it, but some families never receive it. There are thousands of families like ours."

Once the boys finally got into daycare, life improved significantly for the family. Jason and Adam love being at daycare, and Maria now has three days a week for her work. But she knows to make the most of that, because the boys will "age out" of SCDP eligibility when they turn six and transition to kindergarten next year. (Finding supported after-school care is also a major struggle for families of children with disabilities.)

"The system for families like ours is basically denying one parent the ability to work," notes Maria.

Despite their level of disability, the twins receive just 30 minutes total of therapy services every four to six weeks. That includes speech therapy, but only Adam can make use of it. The family can't afford private therapy at up to \$160 an hour, and their publicly funded therapist is not trained in supporting a non-speaking child in learning how to communicate without speech.

Maria has been counting on more therapy time being available once the boys are in school and eligible for B.C.'s School Age Extended Therapy funding, for medically complex or severely disabled children and youth enrolled in B.C.'s At Home Program.<sup>16</sup> Since an April 2023 lift in funding, that program now pays families directly for private occupational therapy, physio-therapy and speech/language therapy at rates of up to \$160 an hour, to a maximum of \$5,760 a year.

Previously, the hourly rate under the program was capped at \$80 an hour, and families either had to use their own money to make up the difference in the therapist's actual hourly rates or see their child go without essential therapies.

"It's not perfect, but I've been waiting for that for years, counting on it being available when the boys are in school," says Maria. "It's very hard for families to get even now – for instance, kids with Down syndrome and many other diagnoses don't qualify – but I have been waiting for so long to be able to have this."

Maria has worked hard to participate in any conversation with government around the plan to shift service delivery to community FCCs for CYSN. Like many families, she is concerned that an end to individualized funding in the At Home Program as part of that shift would mean even less access and control of services for their children.

"The switch away from individualized funding feels punitive," she says. "It's like government is saying that we are using it wrong, can't be trusted, and therefore need them to manage us. But even cerebral palsy is so very different for every child that experiences it, even for my two sons.

"One of my boys can walk but can't do long distances, and I'm actually worried that if B.C. went with the hub model, he wouldn't qualify for equipment. Once again, our families will be having to be evaluated, and answer the same questions again – essentially, 'How disabled are you?'"

Long waits in the health system are complicating life for the family as well. One of the twins needs an operation to stop his ankle from fusing in a way that would leave him unable to put his foot flat on the ground.

"Yay that a specialist has finally opened shop at BC Children's Hospital as of 2020, because we'd been thinking we would have to remortgage our house to get this operation done in the U.S.," says Maria.

"But even though cerebral palsy is the most common [motor] disability for children, we've waited almost two years for a consult with her. If we had bazillions in income, we'd have gone to the States by now."

CYSN systems exist to support families, says Maria. But too often they simply add more stress and frustration as families struggle to identify and access scant services that may not be available to them even if they're eligible.

"I know these are not bad humans in government, so I do try to think, why are the systems not working?" asks Maria. "Is it because they don't know how it is for families?"

<sup>16</sup> <https://www2.gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/support-needs/complex-health-needs/at-home-program>

## Preschool – Birth to age five

The preschool years from birth to age five are some of the toughest years for families of children with disabilities.

These are the years when families are still adjusting to life with a child with disabilities. In many cases, they may not even know their child has such needs until the child is a toddler or begins school, when developmental challenges or distressed behaviours can become more obvious.

Two-income families are coming to grips in these early years with the worrying realization that one of them may no longer be able to work outside of the home because they need to be their child's full-time caregiver, case manager and advocate. This reality is a key reason why families of children with disabilities are also more likely to be lower-income families, a situation that brings its own stresses.

“I gave up employment to care for my child after birth, so have been unemployed for 18 years,” wrote one survey respondent. “We live on a single income and my spouse often struggles with holding a full-time, demanding job and coming home to help care for our 24/7 young adult. It is incredibly difficult.”

These are also the years when families of children born with physical and developmental disabilities have to make the extremely difficult transition from hospital-based services – which in B.C. means a high standard of care that meets every need – to community services that are resourced tenuously.

Two of the families interviewed for our 2020 *Left Out* report spoke of the shock they felt after going from the all-encompassing and round-the-clock care of the neo-natal intensive care unit (NICU) at BC Children's Hospital, to feeling completely abandoned once their stabilized but still medically complex children were released from hospital.

“My husband and I rang up more than \$4,000 in parking costs during our twin sons' five months in NICU. And we were proud to pay it, because the boys were getting such great care,” recalls one mom interviewed for this report. “I wish I could go back in time now and tell myself ‘Save it. You're going to need it.’”



## Line up and wait

Once families begin to recognize in these early years that their child needs support, they will then typically face a difficult period of trying to get a diagnosis or an assessment to understand what is going on for their child. They will enter into a complex system of services that is difficult to access and populated with multiple gatekeepers operating under different rules. It will be up to them to discover what their child might be eligible for.

“The most amazing thing would be to have complex care coordinators – the liaison between all the different specialities and services,” says one mom. “There are just so many things for families to keep up with. It’s so confusing, and so hard to keep track of who’s responsible for what.”

Wait lists in B.C. for assessments for an autism diagnosis are currently averaging 81 weeks and more than a year for diagnostic assessment services through the Complex Developmental Behavioural Conditions program,<sup>17</sup> meaning some families are having to wait significantly longer – vital years in a child’s brain development are being missed because of not yet having a diagnosis that triggers service provision. Assessments that require physio, occupational and speech therapists are delayed by a chronic shortage of such specialities in B.C.; families who can find the funds can seek out therapies privately, but waits are growing there as well.

The tremendous variance in publicly funded support for families during the preschool years adds to the challenges. The current system provides limited supports to children with specific diagnoses, but many diagnoses are not eligible for any publicly funded services.

The families RCY spoke to report much variability in what supports are available to them, and how hard they have to work just to find out what they might be eligible for.

“Why isn’t there a list? One place where you could go to find all the things that you might be eligible for and a parent can follow it out?” asked one mother. “Instead, you sit waiting for a diagnosis and have no idea. Parents have to scramble around finding other families to help them.”

A survey respondent with a child with autism recalled having to scramble just to understand the diagnosis her child had been given, let alone where to find supports.

“When my kids were first diagnosed, I knew nothing about autism. How was I supposed to find a service provider? Hire behavioural interventionists? The amount of work and responsibility placed on parents is unreasonable.”

Families who qualify for the CYSN At Home Program are eligible for physiotherapy, occupational therapy, speech/language services, and specialized equipment for their child. Some of these families, along with others, will be eligible for Nursing Support Services (NSS), a health authority program for children with complex medical needs.

But there’s a big difference between being eligible and actually receiving services, for reasons ranging from insufficient funding to long wait lists, or the lack of health professionals. The rural/urban divide adds to the challenge. Families report trying to glue together bits of service to try to give their child what they need, but that it feels tenuous.

“The web of support our family has built is so fine, so detailed,” says one mom. “We’ve had a couple experiences of a slip, and it pulls everything apart.”

<sup>17</sup> Information received by RCY from the Ministry of Health, July 7, 2023.

## Struggle for child care

Virtually all B.C. families have to work hard to find child care. But those challenges are exacerbated for families of children with disabilities, who may require a skilled classroom aide in order for their child to be able to go to daycare. B.C. funds these aides through the SCDP, but families report many barriers to accessing the service.

SCDP operates through contracts with community providers, and is intended to provide consultation, extra staffing supports and staff training to child care providers and early childhood educators to ensure inclusive child care for all B.C. children.

But in B.C.'s urban regions, eligible families may still not be able to access support because funding has run out due to demand. In rural/remote regions, the funds may be available, but the qualified staff are not, or there are lengthy training delays.

“The supported child care system is not working,” says a participant from the ad hoc advisory group of provincial advocacy organizations that consulted with RCY for this report. “Essentially, parents have to get to the top of two waiting lists at the same time – the wait list for funding for an education assistant for your child, and the wait list for a daycare with an opening.”

The inability to access aid to support their child at daycare through public funds can push families further into economic instability. They are unable to get a needed break from the intensive needs of their child through the support of child care and unable to work. “Government is basically denying one parent the ability to work,” says one mom.

Even families who are prepared to pay out of their own pocket for an additional support person at a daycare face barriers. While public funds go toward subsidizing the cost of child care for many Canadians, there is no requirement on child care providers to accommodate children with disabilities at their centres. Child care centres are often private businesses, which are not subject to the same level of scrutiny in terms of anti-discrimination laws such as B.C.'s *Human Rights Code*.

And even when a daycare centre agrees to take a child with a disability, the burden is too often on the family to find and fund the support person. The research is clear on the importance of supporting children with the right services and quality child care in their early years, and to make sure they are hitting vital developmental milestones. That work is particularly important for the B.C. children whose early-years supports were additionally compromised by the pandemic, increasing their vulnerability.

“I was willing to pay for daycare long before I got it but couldn't find people to do that work in our region,” says the mom of a young boy with autism. “I found a spot at one daycare for \$375 a month, but they wouldn't take him because I had no support person at that time.”

As we carry on into the next section looking at the early school years, here's the story of Lucia and their son Eduardo, growing bigger every day as his family tries to manage in a two-level, inaccessible rental in the Lower Mainland that they have been in since he was born.

Their story reveals the complex, multi-layered issues that families are facing. First and foremost, Lucia's family needs accessible housing. But their story also highlights the problems of systems that don't “talk” to each other, all with differing eligibility criteria and without sufficient flexibility to meet each child's unique needs.

## Lucia's story

In a theoretical world, seven-year-old Eduardo is considered a “two-person lift,” a designation that signals to any professionals working with him that two people are needed to carry the growing boy safely from one place to another.

But in the real world, Eduardo's mother and father carry their disabled son by themselves every day. Up and down the stairs at their second-story rental home in the Lower Mainland. To and from school. From room to room in a house too skinny to accommodate a wheelchair.

B.C.'s housing crisis has affected families of children with disabilities harder than most. In Eduardo's case, parents Lucia and Alexander have three children, but three-bedroom co-op housing is scarce. They urgently need out of the rental market so that they can create an accessible home for Eduardo.

Eduardo suffered a massive brain injury from liver problems soon after birth, developing a toxic form of jaundice known as kernicterus. It left him with severe cerebral palsy, breathing difficulties, chronic pain from dystonia, and unable to see or hear.

“We've tried for co-op, BC Housing, subsidies,” says Lucia. “Because we need a three-bedroom, we will have to wait much longer. It could be years. But for sure we need to have something, because our son is growing.”

Eduardo has an educational assistant (EA) with him at all times since starting elementary school in 2021, and that has been a great support, says Lucia. But the family dreams of having a caregiver to help at their home as well.

B.C.'s CYSN system parcels out funding for families depending on a child's diagnosis, age and severity of disability. Some children like Eduardo have disabilities that, from a systems perspective, aren't quite severe enough to meet a funding requirement, but are still very challenging for families who are denied that support.

Eduardo, for instance, doesn't qualify for B.C.'s NSS because his breathing difficulties aren't quite severe enough to require a breathing tube.

“So that means we don't qualify for nursing support, and it could be that our son doesn't need a nurse. But he does need a skilled care aide,” says Lucia. “I know a lot of families who really need that. Just having a care aide would make such a difference.”

Lucia's advocacy work on behalf of CYSN families has kept her in the loop around the government's plans for a major change to how CYSN services are delivered.

Up until Premier David Eby paused the plan indefinitely last fall, the government had been preparing to transition existing services to a FCCs model, ending individualized funding to families of children with a diagnosis of autism. (Pilots are going ahead in four regions of B.C. in the North and Okanagan, however, as the Requests for Proposal had already been submitted before Premier Eby's announcement.)

Asked about government plans to shift to a hub model for services, Lucia thinks the model could work well for her particular family. She likes the idea of centralized services for Eduardo.

But what weighs on Lucia far more than the question of hubs is how much this latest political decision by the provincial government will end up delaying supports even longer to families who really, really need them now.

“We are in need of help right now. It's incredible that this dialogue is taking years and years,” says Lucia. “Time is flying and my son is not getting the supports he needs. Before you know it, he'll be 18 and out of the system.”

## School years: The first five years

Families of children with disabilities each experience the start of the school years differently, with multiple factors in play.

Some of those factors are related to the current CYSN system and the differing levels of services and supports a child is eligible for depending on their diagnosis. Others are about how individual schools choose to manage the bulk funding they receive from the province for the children enrolled at their school who have been designated as having a disability. Where a family lives, whether they have funds for private supports, and how much energy they have for the hard, constant work of advocacy are also major factors.

The local health authority plays an important role as well. For the 10,600 school-age children and youth with complex medical needs and/or chronic health problems in B.C., for instance, their ability to attend school can hinge on whether the health authority is doing enough training to meet the need for skilled EAs needed for a child to go to school.

There were 86,615 students with disabilities enrolled at B.C. schools in 2022-23, up 4.6 per cent from the previous year – which in turn was up 5.7 per cent from the year before.<sup>18</sup> The Ministry of Education and Child Care reports 14,700 EAs working in 28,254 B.C. classrooms – roughly one full-time EA for every two classrooms.

Enrollments of children and youth with more significant disabilities generate per-student funding for schools based on three levels of need:

- Level 1 (physically dependent or deafblind), \$44,850
- Level 2 (moderate to profound intellectual disability, physical disability, chronic health condition, visual impairment, deaf or hard of hearing, autism spectrum disorder), \$21,280
- Level 3 (intensive behaviour interventions or serious mental illness), \$10,750.<sup>19</sup>

Schools make their own decisions as to how to allocate those funds. Districts received \$878 million from the provincial government for the 2022-23 school year in supplemental funding for students with designations in low-incidence categories, a basic per-student allocation of \$7,885.<sup>20</sup>

Some families whose supports were negligible or non-existent in the pre-school years report feeling significantly more supported once their child is school-age. Others report feeling like they've lost control over the services their child receives and that their child's support has decreased without explanation.

For families of children with physical disabilities, school may be the first time that they've actually had another person – an EA who is with their child for the entire school day, for example – helping them care for their child.

<sup>18</sup> Ministry of Education and Child Care Estimates Notes (2023).

<sup>19</sup> Ministry of Education and Child Care Estimates Notes (2023).

<sup>20</sup> Ministry of Education and Child Care Estimates Notes (2023).

With decisions around support largely left up to individual schools in these years – and no requirement for transparency or explanation – some families have a sense of a new level of gatekeeper shutting them out. The lack of cross-ministry co-ordination leaves families to tackle a whole other system with a different set of criteria for the type of support their child is eligible for.

“I shouldn’t be made to feel guilty because I’m trying to get the therapy that my son needs,” says one mom. “I know these are not bad humans in these systems, so I do try to think, why is the system not working? Is it because they don’t know how it is for families?”

Changing schools was common among the families interviewed for this report. Desperate to find something that works for their child, families find themselves switching from public to private schools and back again, meanwhile testing out faith-based schools, online schooling and homeschooling.

“It’s not like I have a philosophy on any of that,” says one mother. “I’m just looking for what’s best for my child.”

All families report a common experience of having to repeatedly fight once again for what their child’s needs. Whatever struggles they surmounted in their child’s first five years, they are back having to surmount all-new ones in a different system. Several families noted that the attitude of school administrators makes a significant difference as to whether their children feel connected and included.

Families agree – none of it comes easy.

One mom notes that, while it felt wrong that she had to be the one training her child’s education assistant in how to work with her son, it spared her many problems later when she was no longer being called constantly by the school to come and get him.

Here is her family’s story, which highlights another reason why parents fight so hard in the preschool years for services. That work lays an all-important foundation for better support once they are school-age.

## Ashley's Story

Desperate to get her son assessed for autism before he was school age, Ashley finally had to use part of the family's RRSP savings to buy a private assessment after waiting more than two years for a publicly funded one.

But three years on, that decision has made all the difference now that Xander is coming up seven and able to get the school supports he needs. That wouldn't have happened if he'd still been waiting for a diagnosis when he started school, says mom Ashley.

"He loves school so much, and gets upset when he doesn't get into class fast enough," she says. "He can't go in until 9 a.m. when his educational assistant (EA) starts, and the first year was him screaming in the car because he wanted to go in so badly."

Ashley still had to do a lot of advocacy with the school to secure a full-time EA for Xander, who is non-speaking and has only recently learned to feed and dress himself. But with Xander now in school for six hours a day and additional child care in place, Ashley has time and energy for her paid work.

"I'm in a happier, more peaceful place," says Ashley, a newly single parent settling into the routine of shared parenting of Xander and his older sister with their dad, who no longer lives in the same small community in northeast B.C.

"I don't feel like I'm struggling like I was. I sleep better, Xander is eating better. But that didn't come about naturally. I had to fight for it."

B.C. families approved for individualized autism funding receive \$22,000 a year for a child up to age six, which can be used for any qualifying service, support or therapy that the family chooses. But once school-age, funding is provided to schools to provide some services and families receive \$6,000 annually.

That was a challenging transition, notes Ashley. As a pre-schooler, Xander had benefited from one particular program for children with autism. But at a cost of \$16,000 a year, Ashley couldn't afford to continue it once he turned six and could only access \$6,000 a year through AIF.

Nor could she afford to continue his sessions with occupational and speech therapists, whose rates are around \$150/hour.

"But he's getting some of those therapies now through school," Ashley says. "Now, I'm using the money we get for equipment that would help Xander, or for a behavioural therapist to do swimming lessons with him."

Like other families receiving individualized funding through AIF, Ashley was alarmed by initial government announcements of an end to the program, and relieved that Premier Eby put that plan on hold last year. But she understands why families getting nothing at all right now might be angry at the waffling and delay.

"What's actually wrong here is that it's parent pitted against parent in the system we've got now," says Ashley. Every parent deserves support and should not have to fight with each other to get it."

With a general lack of communication and absence of case co-ordinators – or even a detailed list of eligible CYSN services – Ashley says families are left to scramble to find out what they might qualify for in terms of support. Xander turned out to be eligible from birth for a number of supports under B.C.'s At Home Program for children with specific special needs, but Ashley only learned about the program when he was five.

"I still had to fight for it, but they ended up telling me that someone should have told me ages ago that Xander was eligible," she says. "Even the child development centre didn't know."



Ashley senses that reliance on charities such as Variety BC to help meet a child's basic needs is increasing as families report scarce supports and a general feeling of having to fight for every little thing.

"Why are parents left to scramble around finding other families to help them know what supports they might be able to get?" she asks. "You sit for two years waiting for an autism diagnosis and have no idea about anything.

"For At Home Program supports, I actually had to go to the ministry building to find out how to get on it. For respite, it took two years after Xander was referred. He's finally got a lifeskills program now, but I had to stand outside the person's window at my child development centre to get her attention after months of emails and phone calls going nowhere. Why is it always such a fight?"

Ashley identifies a particularly urgent need for more child care for school-age children with needs and more training for teachers on working with them.

Parents need paid work, she notes, but they can't hold down a job in the absence of a daycare that will accept their child, or if the school is phoning them multiple times a week to pick up their child because of distress behaviours.

"Teachers are getting two weeks of training on CYSN. That's not enough," she says. "Parents, I hate to tell you this, but you're going to have to help train the EA for your child. For a month, it's going to suck, but then you won't be called every day to pick up your kid."

## School exclusions

The impact of long-delayed reform and expansion of CYSN services is being significantly worsened by a rising rate of school exclusions for children and youth with disabilities in B.C.

Schools are increasingly putting the burden on families to figure things out when a child's distress behaviours or physical needs are more than the school is able to take on. That is leading not only to increased exclusion of children and youth, but adding to the challenge of a parent being able to hold down paid work, in light of them having to be ready to drop everything when the school calls.

With the majority of CYSN supports and services delivered through the school system once a child is six, school exclusion also jeopardizes children's access to essential therapies and deprives them of social inclusion and their right to an education.

Families we interviewed, whose children have been diagnosed with autism or FASD, say it's common to be called to collect their child due to their child's distressed behaviours. Other families with children who have complex medical issues say delays in health-related training for educational assistants result in their schools telling them that their child can't come in that day unless one of the parents can act as their assistant.

"Learning differences are not being properly funded or supported in public schools," wrote a survey respondent. "Waiting until Grade 4 for a school-based psych evaluation – when it is well-known several years prior that a child has a learning disability – is ableist, traumatizing, and sets the child up for being years behind their peers, which impacts their mental health."

The BCEdAccess Society has been monitoring family experiences of school exclusions of children and youth in the province for the past five years. Its 2022-23 survey<sup>21</sup> of 403 families turned up almost 6,000 incidents of school exclusion, with between 20 and 25 per cent of those exclusions continuing for four months or more.

The number of reported exclusions lasting four months or more jumped 173 per cent over the previous year. Kindergarten and Grade 1 were the most excluded grades, each accounting for 12 per cent of total exclusions.

A lack of capacity in Nursing Support Services (NSS) contributed to an increase in exclusions for children with complex medical conditions in schools. Physical disability or chronic health impairment used to be one of the least impacted categories of disability in terms of school exclusions, but it has moved into second place in the last two years.

“Over the last couple of years, NSS has been realigning their practice with their policies, resulting in some shocks for families who were unable to send their children to school because the [nurse] delegation to school staff had not been enacted,” notes BCEdAccess in its report. “Several students were not able to attend school for a month or more.”

RCY’s provincial advisory group members are increasingly hearing from families who have been told by their schools that their child can no longer be accommodated.

Blame that on the “very limited number of specialized staff in schools to support kids across the board, whether the issue is behavioural, deaf/blind, any of it,” notes one group member: “It means kids are not attending school, or are in a perpetual loop of leaving school and trying to come back.”

The outdated policy manual that informs the Ministry of Education’s approach is another major barrier, say special-education advocates in B.C. The manual hasn’t had a substantial update in almost 30 years, says an advisory group member, and is out of step with much of what is now understood about children and youth with disabilities.

For a child to receive support through their schools for mental health or behavioural conditions, they must first be connected to community support. That’s a whole other barrier given the province-wide labour shortage of professional therapists and specialists.

“Support at schools is supposed to be needs-based. But in practice, without any designation, many students get absolutely zero support,” says former BCEdAccess Executive Director Tracy Humphreys. “This includes students with ADHD, FASD, Down syndrome, many types of rare disease, mental health needs and dual diagnosis.”

Some families are left scrambling when the school tells them that their child can’t return until the family organizes a team of health professionals for a school consultation. That’s “very nearly impossible” to make happen, says Humphreys.

“It feels like a stalling tactic. I can literally think of six kids right now who have been out of school for months.”

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<sup>21</sup> <https://bcdedaccess.com/2023/09/13/media-release-exclusion-tracker-report-2022-23-reveals-alarming-trends-in-patterns-of-exclusion/>

Here's one family's story of the long wait for trained school staff for their medically fragile son. The wait for an educational assistant trained to support their son left the family facing the difficult choice of either seeing their son excluded from school or figuring out how to juggle their own busy schedules around being at school with him so they could manage his care needs themselves.

### Jenna's story

It has been a harrowing couple of winters for Judah and his family. The seven-year-old has been in and out of hospital seven times with life-threatening respiratory problems – COVID, for one, but other viruses circulating everywhere in B.C. in the cold months weren't easy either for a boy with lungs that don't work as they should.

The stresses of severe illnesses and lengthy hospitalizations have been hard on Judah's parents Jenna and Koby, and on the family's three older children. Jenna wishes there was even a little support for mental health needs in B.C.'s programs for children with chronic health issues, but families either have to pay for that privately or do without.

"We're coming out of a pretty traumatizing few weeks," says Jenna. "If Judah is sick, he's going to hospital, and he'll be admitted, and we have three other kids at home. Mental health is so important for all of us when we're going through things like this."

Born more than three months premature, Judah spent the first six months of his life in neo-natal intensive care units, first at a community hospital and then at BC Children's Hospital. Underdeveloped lungs are a common issue for children born prematurely; Judah also has severe quadriplegic spastic cerebral palsy and requires a feeding tube.

The Vancouver-area family is now paying out of pocket for some of the therapies that Judah needs routinely, which Jenna says is probably why she's finally feeling like they have sufficient support for him.

They receive support for certain therapies through B.C.'s At Home Program for medically complex children, and Jenna is grateful for the lift in eligible amounts for those therapies so that parents aren't having to top up therapists' fees, as was the case for many years.

Like all parents of children with disabilities in B.C., it's up to Jenna and Koby to manage their own self-care and avoid injury from the highly physical work of caring for a growing child with severe physical disabilities.

Jenna admits to feeling just a bit of resentment when she hears paid care aides talking about their access to a full range of personal-care services through their benefits plan, which help them stay healthy doing the same tasks for Judah that his parents perform daily.

"For the parents, there's zero support for stuff like that," says Jenna. "I've spent thousands of dollars on physio for myself just since January because of a wicked shoulder injury from carrying Judah."

Judah is enrolled at a private Christian school, which was something that virtually every health professional advised her to do when Judah hit school age, she says. They told her such schools provide better support for children with disabilities and Jenna confirms that has been her experience since Judah began school.

"We've felt support from this school from the get-go, though I know that can really vary for families. With kids like this, nobody's getting a course in advocacy or case management – we're just winging it."

But even with the school's support, she has twice bumped into significant delays in the training of aides at the school to be able to work with their son. The problems appeared to arise from a combination of staffing changes at the school along with lengthy wait times at the local child development centre that provides the training, says Jenna.

Both situations have required family members to step in with daily visits to the school for a month or more to provide the specific supports that staff can't do until they are trained.

"Judah has a [feeding] tube now after his last hospitalization, and I've been going to his school every day at noon to feed him until they get the training, which can take a while," says Jenna. "Last fall when he started kindergarten, the staff needed training in how to do lifts. That took a month, which meant I needed to go to the school twice a day for that entire month to do those lifts.

"For that one, we'd been meeting with the school for the three months before that so they would be ready for Judah starting kindergarten. But the training didn't happen before he started school."

The family rents their house, which is not accessible but has been modified by Jenna and Koby with the landlord's permission to at least have ramps at the door. They also had to buy a wheelchair accessible van, something that B.C. charities no longer help families with. "That was \$40,000 right there," notes Jenna.

It all makes for a challenging life. Even just figuring out a summer holiday plan that will entertain the family's three older children while being workable for Judah is a major undertaking.

"But by the grace of God, our faith has carried us through. We are so grateful to have Judah, and that gratitude keeps away the bitterness," says Jenna. "There are benefits to having a non-verbal child in a wheelchair – when we take him to hospital, he's so sick, but there he is, smiling at everyone."

## Social exclusion

Attending school is about far more than academic learning, bringing important experiences of peer inclusion and participation and connection within the wider community. The experience of school closures during the pandemic revealed just how important the classroom is for children's learning and mental health and the longer-term impact on those children will be felt for years to come.

But while the pandemic may feel "over" for the majority of British Columbians, many families of children and youth with disabilities continue to struggle with the life-changing disruptions it brought about, from loss of paid income to delays in important surgeries and therapies for their child.

Virtually all children and youth in B.C. missed significant periods of school in 2020 and 2021, but families of students with disabilities tell us that their children are still having to miss school at times, whether because they have precarious health and can't risk getting COVID, or because of the staffing shortages and other labour-force disruptions set in motion by the pandemic.

Families are well aware of the social impact that ongoing school absences can have on a child.

"We were still doing Zoom classes long after the pandemic, where the education assistant would send worksheets home and connect us to the classroom so my son could listen in on Zoom," recalls the mother of a nine-year-old.

"But that's not like a classroom where everyone is virtual, just my son. So it felt much more isolated. We could see all the children but my son wasn't able to be there, and was very aware that it was his disability stopping him. That was hard on his mental health."

The single mom in the story below moved from an urban area back to a remote Vancouver Island community during the pandemic. She switched her son to online learning at that time out of concerns for his health, and they have continued with it.

He does well online, she says, but a major downside is that he no longer has the same level of social engagement with his classmates. She recognizes that the early years “are generally easier for that kind of inclusion,” and worries about the impact that missing out on that could have on her son down the line. Here is Bobbi’s story.

### Bobbi's story

Bobbi counts herself fortunate compared to so many other B.C. families who also have children with medical complexity.

She owns her house, which has been renovated to accommodate the needs of her eight-year-old son Fraser. Born with a rare and complex developmental condition, he has functional limitations that require the support of mobility aids including a wheelchair, standing frame and walker.

She has her own business that covers her bills and allows her to work from home. She owns an accessible vehicle (though repairs are always a worry.)

She has a terrific team of private therapists who work virtually with Fraser to strengthen his communication skills, day-to-day abilities and physio needs. And she receives 20 hours of respite care a week through B.C.'s At Home Program – enough that she feels “adequately supported.”

But Bobbi lives with the deeply uncomfortable knowledge that all of that could change at any time. Asked what keeps her awake at night these days, she said it's the uncertainty of not knowing how long any of the carefully managed life she has cobbled together for her and Fraser will last.

Had MCFD gone ahead with its original plans to scrap the current system of support for children and youth with disabilities, for instance, Bobbi would have had to access therapists through a newly centralized hub model and give up the trusted team she has worked hard to create.

That worried her. For children with medical complexity, their therapy team is critically important – not just for therapy but for their support and knowledge of mobility, positioning and communication aids.

The therapists also support families whose children are facing surgeries and other medical interventions. It took a long time for Bobbi to feel like she had the right team for her son.

Bobbi is acutely aware of an unpredictable economy as well. She currently earns just enough at her home-based business to replace the federal COVID-19-related wage benefits that were so helpful during the worst of the pandemic, but she is very aware of how easily that could change.

“There's nothing to fall back on in terms of income support, and so much uncertainty,” says Bobbi.

“It was also scary to see the pediatric hospital system get overwhelmed this winter. It has all left me understanding I have to fend for myself.

“Living where we live makes sense for now, but it's on the edge of the world, and is challenging for accessing therapists, appointments, social engagement, groceries. I worry about other low income families, too. I see them challenged to find any place to rent, and when they do find a rental home, they can't make it accessible for their children.”

Bobbi is grateful for government changes during the pandemic that gave families more flexibility in how they used respite funding. But the base monthly respite rate of \$344 covers fewer than four hours of respite a week, notes Bobbi.

Government has increased funding for certain pieces of essential equipment, she adds, but the families and therapists she connects with are still reporting high rates of rejection over differences between what therapy teams consider “basic” or “medically necessary” versus what MCFD will fund under these definitions.

Bobbi says the At Home Program overall has so many restrictions that she still has to turn to charities to cover Fraser’s needs. She hates having to compete with other families all trying to buy essential equipment that their children need to achieve developmental objectives, health outcomes, and well-being.

“It is not the responsibility of charities to provide basic medical necessities for our kids, but they have been picking up the slack for our failed government programs for years,” says Bobbi.

Fraser was attending public school before the pandemic and loved the social connection it brought, and Bobbi was glad to get him back to class in fall 2021. But then COVID-19 cases began to spike again. She withdrew him in January 2022 and has been home-schooling him ever since, to avoid risking any viral infections that could impact Fraser’s health or her own ability to be his caregiver.

He misses his classmates, she acknowledges. But an unexpected upside of switching to online learning is receiving funding that helps to fill gaps in Fraser’s developmental support needs, such as mobility equipment and communication technology.

Bobbi belongs to a non-profit family advocacy network, and government’s announcement two years ago that CYSN and therapy services through At Home Program services would soon be centralized at community hubs lit a fire under network members. Like Bobbi, many feared losing the right to choose who their child goes to for therapies.

“Our families recently successfully advocated to get the full hourly therapy rate covered by government. What the government was proposing at that announcement was to take that away and force us back to centre-based therapy,” Bobbi says. “They were promising ‘better,’ but they didn’t know us well enough.

“MCFD does not understand how this system is experienced by families. The reality is that any change to the system has to be grounded in a deep understanding of the current system as it is experienced by families with medically complex children. This is urgent. We’ve been ignored for far too long.”

Families across B.C. have urgent and unmet needs on so many fronts, says Bobbi. They need home care supports, income supports, accessible homes and vehicles, mental health supports and more.

“These are absolutely critical elements of family preservation,” says Bobbi. “Without adequate support, families are pushed to the edge. Some find themselves considering whether their child would be better supported in government care. We haven’t even attempted to support families adequately in B.C.”



## Urban versus rural: A question of cost

Bobbi's story highlights another dilemma faced by B.C. families. Living in an urban centre brings increased access to services but a higher cost of living. Living rurally is more affordable but with fewer services.

Two of the families from rural regions that RCY first interviewed in 2020 for *Left Out* have since moved to the Lower Mainland but note a rising cost of living and the loss of a supportive community since making their moves. As well, many B.C. families simply aren't able to move for better access to services and have no choice but to get by with whatever services are available for their child in their community.

Those who live in rural/remote communities also contend with travelling long distances for services, assessments and hospital care – costly and time-consuming for a family, and frequently difficult for the child. One mother in the 2020 *Left Out* report talked of the misery of even a 30-minute drive for her child, whose physical disabilities caused pain for the child anytime they had to be held in one position in a car seat.

A foster mother of numerous children with FASD interviewed for this report has story after story of a frustrated child falling apart after yet another long drive.

"I've been through so many FASD assessments, and they're all 'go here for this, go to Prince George for that,'" she says. "So many families can't go to Prince George. And if they can, these are long assessments we're talking about. The medical alone is two hours, then there's psych, which is many hours, then physio, another hour and a half.

"It's hard to get appointments in sequence, and the kids can't sustain it anyway even if you could. So then there's a hotel stay, food, and so on adding to a family's cost. Why can't a travelling team of therapists come to us?"

Who bears the cost of travelling for services is another point of concern for families, and differs significantly depending on whether a child is biological, adopted or in the foster system. Foster families can access supports to cover travel costs for assessment, therapies and other needs, but those supports aren't available to adoptive and biological parents.

Eighty-six per cent of RCY survey respondents said they have used their own money to pay for assessment, therapy, equipment, and/or transportation costs directly related to their child's service and support needs. Eighty-four per cent spend between \$100 to \$1,000 a month to cover those expenses.

The cost of housing is obviously another major consideration for many families in terms of where they can afford to live.

A WorkBC online tool for calculating the cost of living in different communities brings that point home particularly well. A family could rent a large condo in Smithers for \$1,300 a month, but a similar-size condo in New Westminster costs almost three times that much, \$3,519.

Such harsh realities are what keeps the following family homesteading in a rural part of the Slocan Valley, even though it adds to their challenges of finding therapies and support workers for their daughter. Here is their story.

## Jacquie's Story

B.C. families raising children and youth with disabilities quickly learn that they are either going to get good at problem-solving and advocacy, or life is going to be really hard.

That's certainly true for Jacquie and Frank, who live off the grid with their three children in the Slokan Valley.

Their youngest child – Emma, nine – was born with a rare genetic mutation, Aicardi-Goutières syndrome. Similar to severe cerebral palsy, the syndrome affects brain function and causes muscle spasticity and pain. Emma is unable to walk, talk or sit without support, and will always require round-the-clock care.

Life was hard for families of children and youth with disabilities at the start of the pandemic, but Jacquie says 2021 turned out to be a great year for her family. Her daughter's school introduced a temporary program called "Hospital Homebound" that funded Jacquie to be Emma's teacher, with the support of an educational assistant.

That not only got Emma to school and to her therapy sessions accompanied by a seriously invested and skilled teacher – her mom – but provided some much-needed income for the family because Jacquie was paid for the work.

But all that is over now. Jacquie is back to pinning insufficient services together as best she can to support Emma, now enrolled at an online independent school.

The online school was the better option for Emma and the family, says Jacquie. They're now getting more personalized supports because the school involves parents in deciding how to allocate a student's support funds.

As well, Jacquie can now budget Emma's support funds so that she has access year-round rather than just in the months when school is in session.

"I am so incredibly grateful for the flexibility that this online Christian school has provided so that Emma's program is personalized to her needs," she adds. "It is how it should be, but the public system just does not provide for that."

Once school age, children and youth with disabilities in B.C. typically receive any publicly funded therapies and services through their schools, which are given lump sums from the province based on how many students are enrolled and the extent of their disability.

But parents aren't typically consulted as to how they will be used. That Emma's new school does things differently was a major draw, notes Jacquie.

"They got the special-needs funding when Emma enrolled, but I get to say how to use it," says Jacquie. "We've now got two EAs who come to our home and support us, and funding for physiotherapy for Emma that my partner and I are able to have control of."

"It's been really good, but there are two drawbacks: I don't have the income that I had in 2021 when I was her teacher, and Emma doesn't get to go to an actual school."

Unfortunately, the change in schools has meant the family can no longer access the public school's physiotherapist, who is prohibited by the school district from seeing clients privately. So what used to be a short trip to physio for Emma is now many hours away in a different community.

Jacquie acknowledges that the family chooses to live in a remote area, which makes it more challenging to access services. But on the other hand, it's an affordable lifestyle.

"The fact we can't find a physio is because of where we live. But the cost of living goes up if we live anywhere else. Still, we do need a good physio who we can see regularly. It takes time to understand Emma's body. These children with brain problems, it's different for each of them."

Even while Jacquie says life is feeling "pretty complete" at this moment for her family, the fragility of her support network unsettles her.

She knows much of that worry is about issues beyond anyone's control, but they still weigh on her. Her family doesn't have the extra resources to buy their way out of unexpected developments.

"Having two EAs coming to the house to support Emma is really great. I knew them before I hired them and could tell the online school I wanted them. But what happens if they leave, or retire?" wonders Jacquie.

"One woman is older and we bring Emma to her. The other is fit and strong, so that's great. But what if they can't do it anymore, maybe as Emma grows? Everything is good right now, but what will happen if we can't make that happen?"

To be funded to be Emma's caregiver would be a dream, adds Jacquie. If Emma was in government care, her foster family would be receiving up to \$3,850 a month for her care because of her level of disability, and several times that amount were Emma's needs high enough to require a specialized resource.

But there's no such income support for biological or adoptive parents of children and youth with disabilities.

"Being paid as a caregiver would make such a difference," she says. "It would let our family get by."

Mental health support for families is on the wish list too, she adds.

"There are definitely times when I struggle. I have a good partner, and we're a really good team. But I think a lot of couples in these situations could end up breaking up and the mom left to do all the care."

## Multiple economic barriers

Families of children and youth with disabilities are dealing with economic challenges at every turn, with no end in sight.

The long list of economic impacts include the out-of-pocket costs of services and supports that the family will be paying for; equipment and medication costs; lost work potential due to being the unpaid primary caregiver of their child; requirements for an accessible home and vehicle at their own expense; and travel-related costs relevant to their child's medical care, therapies and assessments.

As primary caregivers for their children, one of the first barriers a couple with a child with a disability confronts is whether both adults in the family will be able to manage paid work. Among our survey respondents, 26 per cent reported having to quit their jobs to provide care, while 38 per cent had to cut back their work hours. Thirteen per cent had to increase their employment hours to pay for caregiving needs.

"I'm a single parent who had to leave their full-time job to care for my child. Financial support via family is the only way we make ends meet," wrote one respondent.

## School years: The first five years

A 2007 Statistics Canada survey found that almost a third of families whose children were the most severely impacted by their disability had experienced financial problems in the previous year. On average, household incomes for families of children and youth with a disability were almost 17 per cent lower than household incomes of other families.

Past Statistics Canada surveys of Canadian families with a child with a disability have established the diverse ways that families are affected economically.

Families report working fewer hours in an effort to provide their child with the care they need, or getting by on a single income to free up the other parent to provide more care. Some report having to turn down promotions or switch work hours or their workplace so that one parent can work nights while the other works days.

The more severe the disability of a child, the more economic impact the family has to prepare for. In the Stats Canada surveys, almost three-quarters of families whose children were most impacted by their disability reported a direct impact on the parents' employment situation.

“I was never able to return to full-time work after maternity leave due to the Supported Child Development wait list, and my kids couldn't go to ANY daycare,” wrote a survey respondent. “Now they are in public school but I still cannot work a regular job, as the wait list for after-school care is over five years long, I am told.

“No options! Totally burnt out, inconsistent income and we really struggle financially with NO support. I don't even feel like a citizen anymore and I was born here. I feel like no one cares and I am a throwaway person.”

Economic impacts have intensified for many families since the pandemic. Families of children and youth with fragile health continue to have concerns around their child attending school now that COVID is an ever-present risk, and those school absences are in turn affecting parents' ability to do paid work.

The difficulties that all B.C. families face around finding affordable housing and child care add to the economic challenges for families of children and youth with disabilities. Those whose child has a physical disability face the additional barrier of finding accessible housing.

Families who own their homes have the option of adapting their house for accessibility, albeit with funds out of their own pocket. But families in the rental market have to seek permission from their landlord to adapt a rental home at their own expense – and then face having to do it again anytime they have to move.

## Middle school to high school

These years roughly encompass Grade 5 through high school for the purpose of this report. As with the earlier school years, virtually all the public funding for children with special needs services in these later years is also channelled through a child's school. Schools receive a bulk payment from the province for children with disabilities enrolled at the school, then make their own decisions as to how those funds will be spent.

The social environment starts to have more of an impact on children in these years. Families talked about the “easier” inclusion of earlier school years, when children are less likely to sort their peers based on perceived differences between them. That sadly can change as children move into pre-adolescence and the teen years, when the judgments of peers start to become more of a factor in a child's life.

So, in addition to ongoing challenges finding therapies and services, some families report new experiences of social exclusion, bullying and incidents of their child being disciplined at school in these years, which can trigger distressed behaviours in their child that can increase the likelihood of a child being excluded from school and told to stay home. Nearly 18 per cent of respondents in the *BCEdAccess 2022-23 Education Exclusion Tracker Report* said that their child had been secluded and/or restrained while at school.

“The school told me supports weren't there for my son because his needs were too high,” recalls a mom of a teenage boy with autism. “But the real issue for him was the social stuff, the mean kids.”

“There was one incident where he kept telling a kid to put a broken toy in the garbage, and the kid smashed his head into a garbage can. The school said it wasn't that boy's fault, because my son was being annoying. So the punishment for being annoying is to be beat up?”

Another mother recalls times of having to threaten to go public to get the attention of school authorities, who were pressuring her to withdraw her son with FASD because his behaviours were more than they could handle.

“I was called into a meeting and told I'd have to home-school him. I refused and pointed out that THEY were required to school him, and that I'd go to RCY, the newspaper and a lawyer if they don't educate this child,” she says.

“I got a call that afternoon that they'd figured something out. My son just couldn't cope in a big classroom, so he was reduced to them doing an hour a day with him, for a year-and-a-half. It worked, but there are times when you have to go to that length to make it happen. You have to make threats.”

All families interviewed by RCY mentioned the absence of mental health services for children and youth with disabilities and their families, both at their child's school and in their communities.

“Even though our son qualified to receive psychiatric help, we now are on three separate wait lists in order to try to access this care,” wrote one respondent. “We have been told it could be over a year in order to access this service. There is no psychiatric support when they need it for the mental-health challenges experienced by families with neuro-diverse children.”

Some spoke of the endless medical trauma that their children with severe physical disabilities face as a routine part of their life, and how urgently both the child and their family needed mental health support to be able to manage ongoing surgeries and medical interventions.

“My son is developing medical anxiety. We go to his appointment, he doesn’t want to take his shoe off so they can look at his foot,” says one mom. “He’s been poked and prodded so much. Just being able to access some help for what he’s feeling would be great.”

Some spoke about their own mental-health needs, and of having to struggle to keep themselves well enough to be the loving parent, advocate and full-time caregiver that their child requires.

By this point in their children’s lives, the families have put in years advocating for their child in an unsupportive system. They are weary of being viewed as the constant complainer when all they’re trying to do is get their child’s needs met.

Families are grateful for the support of the family networks they’re connected to, but too often, feel like that’s the only support they have.

“I was going down a slippery slope before, losing all sense of who I was. It was so rough,” recalls one mother who gratefully found support through a Facebook group of other parents. “I was starting to get so anxious about advocating for my child, too, because it seemed everyone would get angry with me when I’d try.”

Many families also pointed out the urgent need for mental health support for the siblings of their children with disabilities.

“My daughter is kind of like a victim through all of this,” says a mother whose son with autism sometimes terrifies his younger sister with his rages. “It really has a trickle effect if one child is not supported properly. I think that also contributes to higher rates of kids’ mental health, and accumulates on workers, parents, their ability to do their job.”

The lack of cross-ministry collaboration in B.C. adds to every challenge. Any transition from one service system to the next – and there will be many of those in a child’s lifetime – means another battle for families as they fight for what their child needs.

The scarcity of any mental health supports at times leaves families to fear for their child’s life. Some talked of suicide attempts among children with disabilities as young as 10, and of periods of having to hide all the kitchen knives to try to keep their child from self-harming.

Here’s the story of one such family – one that is finally in a period of relative stability after fighting their way into a specialized program for young people with neurodevelopmental disabilities and securing an autism diagnosis to be able to access support funds.

## Jocelyn's story

Life is feeling good right now for Jocelyn and her teenage son Staddon. Years of relentless advocacy and painfully slow waits for the right supports have paid off.

But getting here has been so very hard, acknowledges Jocelyn. It frightens her to think how fragile these happy days are, and how easily they could end.

Staddon is finally in a school program run by a highly respected local service provider specializing in serving young people with neurodevelopmental disabilities. His multiple suicide attempts and stress behaviours are gone, and the knife drawers at his family home in B.C.'s Interior no longer have to be kept locked.

"When I think about the mental health piece and where Staddon was at in 2019 – he was struggling, and suicidal for a while," says Jocelyn. "But he has turned the corner, and has told me 'I'm not even close to that anymore.' We're talking a miracle here in terms of where we were at then, because Staddon wanted to kill himself."

But Staddon turns 19 in three years, and virtually all of the supports that are so helpful for him right now will be lost at that point. He and his mom will be on a new and unknown journey trying to secure CLBC supports. It won't be easy; Staddon will most likely not meet the very restricted eligibility requirements for CLBC services.

"I worry about what's going to happen later, because everybody I know falls off the end of the Earth when their kids with FASD turn 19," says Jocelyn, who adopted Staddon when he was a toddler. "That terrifies me. The other worry that keeps me awake is that I pay for a lot of what Staddon needs out of my pocket, probably \$600 to \$700 a month. Where does that come from if I get sick, or can't work?"

Staddon has had his FASD diagnosis since early childhood, but in 2021 was also diagnosed with autism. In terms of eligibility for services, that diagnosis has been a major help in unlocking supports that Staddon hadn't been able to get up to that point, says Jocelyn.

The family now receives up to \$6,000 a year to spend on eligible supports as a result of Staddon's autism diagnosis, though Jocelyn notes that all of it and more is typically needed to cover the cost of two months of summer camps for him when school is out.

Camps get pricey after age 13, when the presumption is that teens don't need full-time care in the summer break, says Jocelyn.

But Staddon can't be left at home alone while his mom works, or even left alone for more than a few minutes. He's an impulsive and curious young man who is "very good with tools," she says. One time he deconstructed a chunk of the family's fence to build a bike jump in the 10 minutes when his mom was paying less attention.

Being accepted at a partially publicly funded specialty school for children and youth like him has been a major turning point for Staddon. It took four long years to get in and the advocacy efforts of "oodles of people," says Jocelyn, but the change in Staddon after finally enrolling at a school that understands him has been remarkable.

His additional diagnosis of autism in 2021 was a factor as well in finally getting a spot at the school. Children and youth with an FASD diagnosis struggle to find any services in B.C., even though they would qualify more readily if eligibility was based on functional needs and characteristics rather than type of diagnosis.



"It's just a much better fit for him overall," she says. "There are two or three kids in each room with one tutor. It's flexible learning – if things aren't going well today, that's OK until tomorrow. Compare that to his previous school, where he'd be in trouble over things like that. It's so much better."

Jocelyn works hard to find recreational activities that Staddon likes, though each of them has to be considered from the perspective of affordability for the single mother.

She gets some monthly support for tutoring and counselling through B.C.'s Post-Adoption Assistance Program for children deemed to have special placement needs, and other supports through the CYSN program now that Staddon qualifies because of his autism diagnosis.

But Jocelyn still needs to be on a constant hunt for other supports. In the past year alone, she wrote 23 proposals to charities.

"Our families are tired," says Jocelyn of the local FASD community she is connected to. "I'm trying to help a couple of families right now who just have nothing left. They need behavioural supports, but the charities won't cover that for FASD or autism families.

"What we really need is to not to have to fight for everything. I have to explain over and over, get a letter from here, a letter from there. It wears us out."

Mental health supports are strikingly absent from any B.C. programs for CYSN families. Jocelyn is grateful for the counsellor that Post-Adoption Support funds for Staddon; in periods when he refuses to go, Jocelyn can make use of the counsellor's time.

Jocelyn recalls at least one time when she was really struggling with the onslaught of advocacy required of her. "I got so anxious about advocating for Staddon, because it seemed everyone would get angry with me."

Jocelyn wonders what her advocacy will have to look like when Staddon is an adult, and how she might better inform the public about people like her son so they aren't always putting the worst possible spin on some of his behaviours.

"I'm always having to educate people, who just don't get any of this," she says. "Kids like Staddon can't be independent. They aren't understood. He'll be 19 soon enough. I'm very worried about what happens next."

This next family's experiences highlight the intricate web of services that has to be in place for a child with severe physical disabilities to be able to go to school – and how quickly that web can unravel when changes are made to any of the connected services.

## May's story

The challenges of the pandemic are mostly in the past for a Sunshine Coast family. Their son Ethan turns 10 this fall, and mom May is happy to see him back in school and connected to an "amazing" CYSN social worker.

But that's not to say it's smooth sailing. While Ethan has a full-time educational assistant to support him in the classroom and a much longed-for baby sister who arrived in 2021, a number of unmet needs linger on.

For one, Ethan's medical complexities require that he have not just an EA at school, but nursing support as well. Born with a rare condition, nemaline myopathy, Ethan has severe muscle weakness and requires a ventilator at all times.

"One of our biggest challenges is that if we don't have a nurse, he can't go to school unless we come with him. He can't access education like his peers," says May. "When my husband Scott has a day off, he has to use it to be the nurse for Ethan. I can't take that role anymore, because we have the baby now.

"So not every school day happens for Ethan. The NSS program says it's a staffing issue. We have two or three nurses who work with us and if somebody cancels a shift, there's nobody to step in. There has just always been gaps in our care."

As Ethan gets older and the family is less "in the thick of things" trying to manage his many medical needs, behaviours have emerged that are signalling the possibility of other issues that he'll need support with, including mental health concerns.

Like so many other CYSN families, May is struggling to find help for those emerging needs.

Medical procedures are a common aspect of Ethan's life, and his parents had always presumed that having to endure all those procedures were the explanation for how Ethan acted sometimes, especially when he exhibited anxiety.

But the extensive one-on-one time his parents had with him during the pandemic opened their eyes to other possibilities.

"Ethan is medically complex, and there has been a habit to think that a particular behaviour is related to past medical trauma – for instance, the anxiety that he gets being highly related to medical procedures," says May.

"But being home together all that time in the pandemic and seeing these behaviours come up, seeing his sensory issues coming up in new ways, we started to ask about an autism assessment."

The wait for public autism assessment is two years or more, says May, "even once you're on it, and we finally got on it last summer."

"I've contacted people for a private assessment as well, but they've got a backlog too – and when I finally did get to talk to someone, it was a \$4,500 estimate."

The family also tried for a psycho-educational assessment for Ethan, but were told Ethan wasn't high priority because others needed it more.<sup>22</sup>

<sup>22</sup> Variety The Children's Charity received so many applications for assessment for autism or psycho-educational assessment from B.C. families between June 2021 and early 2023 that they had to shut the grant program down, after funding 1,579 of the 2,223 applications. After extensive consultation with the autism community, Variety reopened its grants in October with a focus on kids aged four and under and with a growing list of private autism assessment providers across the province willing to partner with Variety to provide a lower charitable rate to further bridge the gap so that children can get early diagnosis and intervention and the critical resources needed to thrive as soon as possible.

The family continues to struggle on all fronts, from assessments to NSS hours.

"It feels like NSS is looking for ways to cut funding by introducing new rules to make it harder for things to actually work for parents," says May. "For instance, they now limit respite to eight hours of care in a 24-hour period – basically an overnight shift that gives no respite for the caregiver, what with sleep being a rather basic human need to be met!"

May and Scott have never gotten a night away together since Ethan was born. With no guarantee from the nursing agency of trained backup support should a nurse suddenly not be able to make a shift, the couple worries that Ethan could be left with no one to care for him while his parents were away.

Their situation highlights that despite additional respite funding being available to families, those extra dollars mean little in the absence of sufficient human resources to provide the respite.

"It all makes it more challenging than ever for families to access respite," says May. "It just feels like we are always encountering issues that lead us to losing hours, no matter how much we want to use them."

As well, Ethan continues to wait for essential routine medical procedures.

"Ethan has a major surgery coming up that was supposed to be spring 2022, but we're still waiting and they're talking summer 2023. Meanwhile, his scoliosis is progressing, and he's uncomfortable. It's also major surgery, and we need to prepare for time away for him to recover. But how do you prepare when you don't know when it will happen?"

It all leaves May feeling like the unspoken goal of B.C.'s services for families like hers is to keep a lid on spending rather than support children, youth and families well. Even knowing what equipment or supplies a CYSN family could get under B.C.'s At Home Program services comes down to either guessing until you get it right or asking other families what they have received.

"There's no catalogue of items so you could actually see what you can have," says May, adding that informal family networks she is connected to now make lists of what they're getting to share with other families for a better sense of what they might ask for as well. "It's all just word of mouth. It feels intentional, to save dollars."

The load on families is staggering, she adds. They are parents, caregivers, case managers and complex-care providers all rolled into one, with no pay for any of that unless they are foster parents.

"I would say that the biggest need that any family like ours has is caregiver pay," says May. "Here we are, not able to work. For me with Ethan's nursing services being so gappy, I can't work. I can't work and get him ready for major surgery, and be there to support his recovery."

Families with medically fragile children and youth could benefit immensely from having complex-care coordinators to liaise with all the professionals and medical specialists their children will generally need for a lifetime, adds May.

"This coordinator could guide you through all the things you need to stay on top of. Honestly, it's so confusing," she says. "A lot of these things need to be under one government umbrella as well, because it's so hard to keep track of who's responsible for what."

And while Ethan has yet to turn 10, May is already thinking with deep concern about when he's an adult – and to a time when May and Scott have grown too old or sick to care for him.

"I worry what would happen right now to Ethan if something happened to us. I can't think of any place for him but Canuck Place pediatric hospice or the intensive care unit of a hospital were that to happen," says May. "Looking ahead, adult services are poor, and I hear it's a drastic drop in support. I'm so worried about that."

## The family divide

Every family interviewed for this report brought up the significantly higher levels of support available to foster families of children and youth with disabilities, as compared to biological and adoptive parents. According to RCY's survey, 14 per cent of respondents said they have considered placing their child in care under a special needs voluntary care agreement to get the services and supports that their child requires. In addition, 21 per cent of the 68 respondents who have placed their child under a special-needs or voluntary care agreement, said that they did so for the sole reason of getting services, and supports for their child, that they could not get if they remained in their own home.

The difference in the level of support effectively creates a three-tiered system for children/youth and their caregivers.

The best-resourced is the foster system, with paid caregivers and better access to an array of funded resources. The next best resourced are adoptive families of children and youth designated as having special service needs, with families receiving up to \$1,135 a month maintenance for youth ages 12 to 19, and \$849 for children from birth to 11 (if annual household income is \$80,000 or under). These families can also receive other supports for counselling, therapies, equipment and respite.

### Still Left Out: MCFD Caregiver Payments

Category	Monthly Payment	Additional Service Payment*	Total Monthly Payment
<b>Family Law Act (FLA) Guardianship</b>	✗	✗	<b>\$0</b>
<b>Private Adoption</b>	✗	✗	<b>\$0</b>
<b>Adoption through MCFD – Post Adoption Assistance**</b>	✓	✗	
Ages 0 to 11	Up to \$849.36	\$0	<b>Up to \$849.36</b>
Ages 12 to 19	Up to \$1,135.81	\$0	<b>Up to \$1,135.81</b>
<b>MCFD – Out of Care</b> (includes Extended Family Program and Permanent Transfers of Custody under section 54.01 and 54.1 of the <i>Child, Family and Community Service Act</i> )	✓	✗	
Ages 0 to 11	\$1,502.53	\$0	<b>\$1,502.53</b>
Ages 12 to 19	\$1,686.92	\$0	<b>\$1,686.92</b>
<b>MCFD – In Foster Care</b> (includes Special Needs Agreements and Voluntary Care Agreements)	✓	✓	
Ages 0 to 11	\$1,502.53	Level 1 – \$591.90	<b>\$ 2,094.43</b>
		Level 2 –\$1,473.74	<b>\$2,976.27</b>
		Level 3 –\$2,347.67	<b>\$3,850.20</b>
Ages 12 to 19	\$1,686.92	Level 1 – \$591.90	<b>\$2,278.82</b>
		Level 2 –\$1,473.74	<b>\$3,160.66</b>
		Level 3 –\$2,347.67	<b>\$4,034.59</b>

\*Foster caregivers who provide specialized care for children and youth with moderate to extraordinary support needs receive a service payment in addition to the maintenance payment per child or youth. This additional payment recognizes the special caregiving skills and extra time required to meet the needs of a child or youth.

\*\* Post-Adoption Assistance is only available to families who meet the eligibility requirements. Families are income tested and a social worker must determine that the child's situation requires financial assistance.

The least supported are biological families. They are unpaid caregivers who must find their way to publicly funded services or pay out of pocket for private ones if public services are unavailable, insufficient, or a poor fit.

For families of the highest-needs children, this reality can leave some biological parents contemplating the painful thought of whether they will have to put their child into foster care just to get their child the support they need.

“I don’t see why kids with special needs don’t just get services. The dividing line between support for foster parents versus biological parents – what difference does it make?” asks one mother.

“It’s like we’re stuck in an archaic cycle that favours investment in foster families and group homes over natural and biological families.”

One mother put her son into a Voluntary Care Agreement when his needs became too high for his family to manage. It didn’t go well on a number of fronts, she says, but one completely unexpected issue was that when her son was finally returned home, he was deeply disappointed to no longer get the same publicly funded recreation opportunities and personal “treats” that his various foster placements had provided.

Some families acknowledge being envious of the extended health benefits for massages and such that are available to people whose job involves working with their children. No such benefits exist for family caregivers.

As mom Jenna in a previous story pointed out, caregivers such as herself receive “zero support” for such benefits. “I’ve spent thousands of dollars on physio for myself these past few months because of a wicked shoulder injury from carrying my son.”

The family in the following story know all about the complexities of a system that draws a hard distinction between children and youth in foster, adoptive or biological families. Maggie and Scott have been both foster parents and adopted parents, and know first-hand just how much difference that change in status makes in terms of the support a child receives.

“B.C. announced a 47 per cent increase for foster caregivers this spring, and five per cent for post-adoption families. Once a child is adopted, circumstances are very different,” says Maggie, whose story also illustrates the urgent need to support children and youth with FASD.

## Maggie's story

The teen years are challenging for any family. But they've been especially brutal for 13-year-old Ashley and her family.

Ashley is one of four children with FASD adopted by Maggie and her husband Scott as infants, all of them born to a mom who experienced severe traumas and addictions and still does her best to stay in their lives.

Ashley is the oldest at 13. The others are three, four and five, each of them with their own unique challenges and strengths related to their FASD and multiple other diagnoses. FASD is a highly variable and life-long brain condition caused by pre-natal alcohol exposure.

Lately, Ashley's mental health has become a particular concern. Having tried to commit suicide multiple times over the last three years, she had to be placed in secure respite care for a period this spring as her crisis deepened.

Unfortunately, the preventive supports that might keep Ashley out of crisis simply don't exist in B.C., says Maggie.

So many other issues also impact family function.

"If I could get child care, I could use half the respite I need now," she says. "But for Ashley, now 13, there's no option for child care, and the teen programs in our area don't work for her because kids aren't allowed to bring along a support person."

An estimated four per cent of the population has FASD. Crunch the numbers in B.C. and that means that some 38,000 children under age 19 have FASD,<sup>23</sup> and more than 1,700 babies are being born with it every year.

But the condition frequently goes undiagnosed. The characteristics of FASD are easily mistaken for other disabilities. Children with FASD do not receive even close to the same level of CYSN services and supports as children with other diagnoses. The services that do exist for FASD remain scarce and inconsistent from one region to another.

Virtually every family who has a child with FASD struggles to cope because there is so little publicly funded support.

"At the best of times, three of our four children do not sleep through the night, and Ashley might be up all night. She has nine formal diagnoses," says Maggie. "B.C. has a key-worker program for FASD, but I don't need someone hooking us up to a food bank or 'capacitating' me. I need people. I need hands. My husband and I have not been away for three years."

Maggie is a much-appreciated community advocate for FASD families in her region, and a regular presence at advisory tables with government.

She marvels at government's surprise at what seems to be an endless line of families seeking an autism diagnosis for their child. How can that be a surprise, she asks, when B.C. has "only paved one road" to adequate services for children and youth with support needs, and that's through an autism diagnosis?

Children and youth diagnosed with autism are eligible for up to \$22,000 a year in individualized funding to age six, and \$6,000 a year to age 19 in B.C. None of the myriad other disabilities and disorders affecting the province's children and youth receive anything comparable in terms of level of support and choice. That's particularly the case for families of children with FASD, notes Maggie.

<sup>23</sup> Recommendations in RCY's report 2021 report *Excluded* seek to increase understanding, support and inclusion for children and youth with FASD and their families.

"And at the front lines of government services, nobody knows anything. I actually heard the director of service for CLBC saying that people with FASD age into CLBC as adults. That's simply not true."

CLBC services are available only to adults with FASD who also have a co-occurring condition of intellectual disability, or significant lack of adaptive functioning skills.

Maggie supports government's plan to move services for children with support needs away from a diagnosis criteria, and to deliver services more centrally out of community FCCs. That plan has now been paused after concerns were raised on a number of fronts, most especially among families of children with autism who were going to be losing individualized funding under the plan.

B.C. urgently needs a service system that steps up for every child with a support need and doesn't favour one disability or diagnosis over another, says Maggie. Giving children, youth and families what they need will pay back many times over, she adds.

For FASD families, what services there are tend to be available only when the child appears "stable," Maggie says. But holding out for stability can be a very long and problematic wait for children and youth with FASD.

"The reality for many FASD families is that we are never going to live in a place of stability. They're giving us just enough support to get us through crisis, then they take it away and we spiral into crisis again."

Ashley's brother Joshua started Kindergarten last fall. His bumpy first year highlighted how children with disabilities feel it first when there's any kind of pressure on the system, says Maggie.

A neighbouring school is at 200 per cent capacity – so full that two classes have to use the gym at the same time, and the playground has to be compartmentalized by grade. The overcrowding is affecting enrollment at Joshua's school now. For children and youth with sensory issues and a need for plenty of personal space, the chaos and noise of a school beyond its capacity is too much to handle.

"Our kids need space, extra time on the playground. But when you overcrowd schools, you lose those spaces," says Maggie. "When we put pressure on our education systems, these are the first kids to go. And if Joshua can't go to school, where is the support in the community? Where's he going to build these skills?"

Asked what it would take to meet her family's needs, Maggie says she "can't even fathom it."

"There are just so many barriers. I'm dealing with four calls a day just from the school system about my kids," she says. "We talk about falling through the cracks, but the system creates the cracks. How about we start giving bonuses to social workers for the number of programs they get kids into?"

Like so many FASD families, Maggie can hardly bear to think about what will happen when her children turn 19 and "age out" of any special-needs supports. She's already thinking about ways to make the world nicer for people living homeless, just in case.

"A great risk for us is that Ashley will end up on the street. I need to create a society where she's included even if that happens," says Maggie. "None of this is my fault. It's not Ashley's fault, or the birth mom's fault. It just is. And we really need to deal with that."



## No care for the caregivers

The burden carried by families of children and youth with disabilities can't be overstated. Virtually every family interviewed by RCY stressed that the burden is not related to having to care for a child with unique needs, but about the giant volume of work that is required of them just to try to get their child the supports they need.

"I can't be the loving, fun parent as well as the behaviour interventionist, the person administering meds, the case manager, the support worker," says one mother. "It's just not possible."

Respite is virtually always a challenge to find, say parents, whether due to a child's complex needs, a lack of funding, or a lack of trained respite workers. A respite job typically provides no more than a few hours a week for a worker unless a family can afford to pay privately.

There is largely no mental health support for these families or their children unless one earner in the household has a job with health benefits.

MCFD has child and youth mental health teams across the province. However, wait times are lengthy and there are no specialized services or dedicated specialists for children and youth who also have disabilities, as highlighted in RCY's report *Toward Inclusion: The need to improve access to mental health services for children and youth with neurodevelopmental conditions* (2023).

In 2021-22, MCFD reports there were 6,812 children and youth wait-listed for CYMH services, and that the average wait time was 71.2 days. The number of children and youth on the wait list has changed very little since 2019, while average wait times have grown 28 per cent in that time.

Nor are there massage therapy services for the aches, pains and injuries that come from lifting and transporting a growing child with mobility issues. Fewer than 60 per cent of survey respondents said they were able to access extended health benefits.

But more burdensome than all of that is the vast amount of paperwork that families have to keep up with just to continue to receive services for their children. Among our survey respondents, 46 per cent said they have to complete paperwork to access services and supports at least once or twice every year, and 35 per cent said they are having to do it more than that.

"I don't think that people who work in the field even understand the burden of paperwork for families," says one parent. "An example: it took me three applications to get approved for the At Home Program. Each time I was rejected, I'd have to find the time once more to get a doctor to complete the paperwork and have another home visit from a nurse from the program to assess my kids."

"Everyone who worked with us – even the nurses who did the assessments – were really surprised our family was denied services twice. And then you have to wait to apply again, so it actually took me about three years from my first application to get approved. And that's just one application."

Her example underlines the true impact of inadequate resources and long waits for service. Children and youth are being left to wait for years to get the supports that would give them their best chance.

Organizations such as Variety The Children's Charity have long been important funding sources, filling significant gaps in the system to help children and families gain access to programs, services and equipment that government doesn't cover or where they might otherwise have to wait months or even years.

But families report an increasing reliance on charity for essential services such as behavioural intervention or an assessment of disability. That loads on additional paperwork. One mother said she's now "triggered" by every request to fill out forms. Every one of them dooms her to another late night of trying to complete a seemingly endless array of questions that requires her to put her child in the worst light just to receive the funding.

Charities are being turned to more and more for the most basic of needs. More than a third of the families surveyed by RCY said that they have had to apply for funding from charities to pay for services and support for their child over the past three years.

Even basic community supports available to everyone can't be counted on for families of children with disabilities. Children without disabilities and their families typically have an array of options available to them at the local community centre for affordable summer camps and alternative care when school is out. But those programs typically have age cutoffs that shut out older children and youth with disabilities, who still need those supports.

The mother of a 15-year-old son with co-occurring conditions of autism and FASD says she can't possibly leave him on his own at this point when school is out for the summer. She is having to spend his entire year's worth of autism supports on two months of costly summer camps (and very worried about what will happen when he is no longer eligible for those supports at age 19).

She is grateful for the support of local charities in helping fund all the sports-related activities that keep her son doing well, but exhausted from having even more form-filling added to her workload.

"I think we're at 23 grants already this past school year for my son's activities," she told RCY in March. "I believe in doing the work for those kinds of things, but I don't think it should be what I have to do to get him help with his disability. Our families are tired."

Here's a story that brings home the burden of paperwork on a family of twin sons with autism:

## Vanessa's story

Twin boys with autism and related health issues would bring a lot of challenge for any family. But the bigger challenge is all the hard work that parents have to do to access government supports for their children, says a North Vancouver mom worn out by the paperwork and runaround.

"There are always things on my list of things I have to do because government requires it," says Vanessa, whose twin boys are 11. "Right now, I'm having to apply again for the disability tax credit, because Canada Revenue Agency sent me a letter saying I would have to reapply for the 2021 tax year, even though the boys' disabilities are forever.

"So off I go to the doctor again, take the forms, hope they don't mind filling them out again. Meanwhile, I'm having to find my own people to provide respite, because the community agency that gets funding to provide me with that has no one for me. It's left up to me to find my own workers."

The family is paying out of pocket for two respite workers at the moment even though that's a funded support, says Vanessa. That's because one worker is great with her boys but refuses to "go through all the hassle" required by the agency that controls access to the respite funds, while the other is jumping through the hoops right now but can't afford to go without pay in the meantime.

"It's all just a bit much," says Vanessa. "They give you the money, but they make you work so hard for it. That my kids have autism is not my biggest life challenge, it's all the other stuff that goes on. When someone hands me a form, they're asking me to stay up until 2 a.m., because that's the only time I can get it done."

Christopher and Kevin were diagnosed with autism a few months after turning two. Facing a wait list of 18 months or more at that time for a publicly funded diagnosis through Sunnyhill, Vanessa and husband Dunc opted to pay several thousand dollars out of their own pocket for a private assessment so they could access funding and therapy sooner.

Both boys are non-speaking. Christopher's autism has a more severe impact on his life and that of his family; extremely painful gut issues that left him regularly writhing in agony for years have only been sorted out in the past year.

"Everything has a trickle effect in this household, because if things aren't going well for Christopher, they're not going well for any of us," says Vanessa.

B.C. children and youth with autism diagnoses are eligible for significantly more support than those with virtually any other disability or support need. But that's not to say that the processes for accessing those individualized funds are easy or certain, says Vanessa.

There are many strings attached to service access, she adds.

"The system setup through the Autism Funding Unit is antiquated and much more complicated than it needs to be. Families are basically having to guess in advance how they'll use funding, and then having to get approval to transfer that money to accounts that must be created for each professional the family works with – speech, occupational therapy, physiotherapy, behaviour consultant, behavioural interventionist, just to name a few."

If the caregiver guesses wrong or a professional inadvertently makes an error in calculating their fees for the year, the process has to be started all over again.

Issues outside a family's control still end up coming back on the family: Vanessa's respite agency not having available workers, for instance, led to government telling her that her hours would be cut because she wasn't using them, even though the reason she wasn't using them was because there was no respite staff available.

The threat of those precious hours being clawed back and her frustration with the government's "logic" brought Vanessa to tears on multiple occasions.

"Our autism funding for the boys has to be spent by January of each year. I try to use up the funds, obviously, but they make it so complicated," she says. "In general I've tried to use it only for services, because the equipment portion is such a hassle to get through."

The boys' iPads that they require for communicating are an example. Vanessa did what was required in submitting the request to buy the iPads, but was told she'd need to "redo the goals." Back she went to the therapist for more detailed goals, delaying approval for another month.

"And then during the height of COVID when the government was saying families couldn't get an extension to use their funding – even though the people providing the services couldn't enter our homes – I'm seeing government quoted in the media saying it's not a big deal since some people aren't using their autism funds. Such spin! There must be so many families who just give up."

The boys are doing well at their school, with education assistants that the family loves and a supportive administration. But none of that came easily. And while Vanessa works hard to get around at least some of the barriers put in her children's way, other families have no road into services at all.

"The neuro-typical kids' parents have no idea what families like ours go through," says Vanessa. "They are on the smoothly paved highway and we're bouncing around on the side roads full of potholes."

Asked about what the family would need to feel sufficiently supported, Vanessa says one of her biggest challenges is that the systems intended to support her family aren't functioning as they should.

Having to hunt for her own respite workers not only increases the burden on an exhausted parent already on her feet 17-plus hours a day, but turns her respite funding into "Monopoly money."

"My kids have high needs and the burden on me is both emotional and physical. I just try my best to hold things together," she says. "I can't even go out for milk if I have both kids. Don't even get me started on Christmas break, spring break and summer. I could cry thinking about that."

Vanessa worries about her and her husband's health, and what would happen to the boys if their parents suddenly weren't able to be their constant caregivers.

Her husband has already had two heart attacks, including one while out of the country that left Vanessa to struggle as the sole caregiver for two weeks when he wasn't allowed to fly. Vanessa hasn't been able to take paid work in 10 years because her boys' needs are so high.

"I don't think the general public understands that having kids with special needs and high needs affects the family on every level possible – financial, emotional, social and health-wise," she says. "Just knowing we had a backup would make such a difference. The stress of knowing that we don't adds enormous stress to our already incredibly stressful lives."

CYSN families face a multitude of unique challenges, but they also face the shared challenges that many families face: affordable housing; stable and well-paid work; and managing through a divorce. RCY heard stories of new babies, new romances, and major moves among the families that we first spoke to in 2020.

These next two stories highlight how such typical life changes are that much more complex for families of children and youth with disabilities.

The first family made a major move during the pandemic to be closer to services for their son. They are still dealing with the fallout at their new home after putting their struggling teenage son into voluntary government care ahead of their move, only to end up having to fight for his return.

The second family is managing not just the usual challenges that all CYSN families face in finding the right supports for their child but a complicated family dynamic. Their son's distress behaviours are having a heavy impact on a younger sister, highlighting the impact on every family member when children and youth with disabilities aren't getting the support they need.

### Renata's story

Moving to the Lower Mainland from Fort St. John in 2020 during a pandemic was a challenging experience for Renata and her family, and an eye-opener in a time of housing crises and rising costs in B.C.'s urban areas.

But her son Dylan needed autism supports at a level that the small community simply couldn't provide, especially once the pandemic hit and his carefully constructed routines fell apart.

As Dylan's needs escalated, the family sought a Special Needs Agreement (SNA) as the best chance to get him the services he needed. But when he finally came home, after the family had made "an emergency move" south, they realized he had been traumatized by the experience.

Dylan ended up in government care under the agreement for 16 months before coming home in February 2022. The SNA – intended as a temporary and voluntary option for families to put a child into government care while a crisis is worked through – turned out to be a hard lesson in being careful what you wish for, says Renata.

She quickly grew concerned that the system seemed to be pushing her and husband Marco away from Dylan. Now 18, Dylan is back living with his family but has trauma from some of his experiences in care, says Renata.

"We made sure we had control throughout the time that he was in care, even if he needed a Band-Aid," says Renata. "But there's still so much disconnect when these kids go into an agreement."

The family had presumed that because they had asked for help from MCFD, their case would be managed more collaboratively as compared to when a protection order is in place, and that they would be consulted throughout as decisions were made about Dylan.

That wasn't the case, says Renata. "Families need to be treated as guardians and parents."

Putting Dylan into foster care was a painful decision for the family, says Renata. "But we had to break the cycle: ministry – home – hospital – ministry – home – hospital. He went through three placements in that period. It's so heartbreaking that it took all that."

Now that Dylan is home again and 18, another transition is looming.

He will "age out" of B.C.'s CYSN services when he turns 19. School also ended for him this year when he graduated from Grade 12.

His school years were far from ideal, says Renata, with teachers who don't know how to work with a child with autism and overloaded educational assistants juggling too many students. But Dylan enjoyed school and the structure it provided.

As Renata looks toward the future, she sees a black hole.

"What do you do for a teen coming to the end of school but not able to look at semi-employment yet?" she asks. "He doesn't do well with other people with disabilities. He's got trauma to deal with now from being in care. A broken system has broken our child, and now we've got the broken child back."

Dylan's younger brother Joel, six, has now been diagnosed with autism as well. That has challenged the family in a whole other way, as it means they are tapping into even more of their scarce personal resources to be able to carry the costs of autism supports for two children. The wait for reimbursement from the province is as long as three months, says Renata.

The family is eligible for up to \$6,000 a year in individualized funding for services and supports for each child, though this is the last year that Dylan will qualify.

"What family has a spare \$2,000?" asks Renata. "If we put it on a credit card, we end up paying two months or more of interest, and it leaves us with no card space for other needs. Families like ours can't wait that long to get our dollars back."

The issue here is that when the Autism Funding Branch is not able to pay service providers in a timely manner, families are pressured to pay them directly out of their own pocket rather than risk losing that provider. This leaves the service provider to reimburse the family when they eventually get paid.

Other factors are also leading to economic exclusion for the family.

Renata is on disability benefits herself, but those benefits have not kept up to the cost of living. She worked a food-delivery job for a while because she could take her younger son along, but that ended in the pandemic as risks of COVID exposure for the boy became too great.

The interim financial supports provided by the federal government during the pandemic actually put the family in a better financial position for that period than is the case now, says Renata.

"I was able to get CERB [Canada Emergency Response Benefit] and some extra caretaker funding. Having that \$2,000 a month made a real difference," she says. "Having that permanently would be so useful. In a perfect world, we'd have a guaranteed income."

What keeps Renata awake when thoughts turn to her family's needs, and those of all the other British Columbian families raising children and youth with support needs?

"I think that would be the economy – the financial side of things," she says. "There's an online group I'm part of, Mamas for Mamas, and I hear about food shortages and struggle. For us personally, I've got a credit card, my husband works, and I'm on disability. But there are still days when I think, how can I buy these groceries?"

## Jennifer's story

Things are so much better now, but the years before 13-year-old Nicholas got on his medication have left a mark on his younger sister.

Hannah rarely needs to employ her safety plan anymore that mom Jennifer developed for her for times when Nicholas's distress behaviours started to scare her. But it hasn't been an easy sibling relationship, and Hannah's mental health has suffered.

"In a family where there's a special needs child and the intervention doesn't happen properly, that can really affect other siblings," says Jennifer, who works in the field.

"My daughter is kind of like a victim because of all of this. She goes to a monthly group for children with siblings with autism. It really has a trickle effect if one child is not supported properly."

Hannah and Nicholas no longer go to the same school together, and that has really helped, adds Jennifer.

"I try to separate these two kids as much as possible. There used to be a lot of issues in school with the two of them, because Nicholas would seek her out, frighten her. Now, we can even do short times of play, and they play well together. It feels like it's a bit more typical parenting. We're never going to be in the clear completely, but things have changed significantly."

The complex household dynamic for the Lower Mainland family has been complicated by the fact that Jennifer's ex-husband has a completely different view of Nicholas's disability and how it should be managed. That disagreement led to long delays first in getting Nicholas assessed, and then getting him on medication.

He was diagnosed with autism at age eight. His mom Jennifer had been trying for that assessment for years at that point, but the boy's father fought her at every step.

Now that a court order has at least let Jennifer get Nicholas on medication to calm his distress behaviours, he is loving school, where he's well-supported. With the help of an occupational therapist and a behavioural interventionist, Nicholas is doing significantly better than he was when RCY last talked to the family in 2020.

"He's consistent now. He knows what he has to do, and that sometimes I need to take him to appointments," she says. "He has had some play dates, and met a boy at a park who is now a friend. He's doing well."

But Nicholas spends every other weekend at his father's home, and the father's refusal to acknowledge that Nicholas has autism and needs services is an ongoing challenge.

His mom managed to find him a social skills program, for example. But the father refuses to take Nicholas when it's his week with the teen. The program has a hard rule about attendance, which puts Nicholas at risk of being shut out due to missing sessions when he's at his father's house.

On the upside, Nicholas is doing so well in his first year at middle school that school authorities have lifted the safety plan they had in place in the event Nicholas experienced one of his once-infamous and frightening meltdowns.

"The school mirrors the strategies the parent uses at home," says Jennifer. "They're great, and we're blessed with a case manager at the middle school who is really supportive. The principal at Nicholas's old school really understood autism, and helped Nicholas do a 180."

Jennifer has a new baby now, born in February. That was a surprise, she says, but Nicholas is thrilled.



A charity grant has allowed Jennifer to hire a behavioural interventionist, though that grant is finished in December 2023. She wishes government still had behavioural consultants on staff to help families develop new strategies and approaches.

"There are definitely supports my son needs to grow into a healthy adult," she says. "I don't want him to miss out on things like going to college, but we don't have tutoring, don't have behavioural consultants to tell behavioral interventionists what to do. They're just going with what they think is best."

Jennifer considers herself a well-informed advocate for her children and appreciates having a government job with the support of her boss and co-workers at the times when life inevitably goes awry. But she wonders how other families with less support manage to hang on.

"I can phone into my job and say I'll be an hour late because the police are at my house. But even I have had some scary times when I've wondered if I'd have to give up my job to be able to deal with all that was going on with my son," she says.

"What about the parents who don't have the knowledge or the time to deal with any of this? Changes need to happen. Please, government, listen to the real-life stories of people going through this."

## High school years and graduation

High school is envisaged as a time of preparation and celebration for students as they step into young adulthood and think about the careers they want to have, the training they will need, the places they want to explore.

These years play out very differently for many students with disabilities, unfortunately. Even the classic moment of crossing the stage as a new graduate is not a certainty for a youth with disabilities.

B.C.'s *School Act* is guided by a mandate aimed at creating "the educated citizen" through the provision of intellectual, social and career development. But families interviewed for this report note timelines and age barriers within the system that are resolutely neuro-typical, and don't allow for a slower pace for a young person with disabilities to mature and develop.

One mother spoke of the mental anguish her daughter experienced in high school as she was pushed into taking on more than she could manage in order to graduate before age 19. "Our system is creating mental health crises for people when there doesn't have to be one."

Coming to the end of the school years can feel like preparing to step off a cliff, say families. They know that any services secured to that point for their child will be coming to an abrupt end. Tax benefits and credits for families of children and youth with disabilities also end, regardless of whether a young person will continue living at home and needs the support of their family.

Individuals applying for CLBC must meet the eligibility criteria. The five-year average for new registrants who are deemed eligible for CLBC services is 1,388. Everybody else will have to find their own resources to cover the costs of services they need, outside of medical care.

Parents understandably worry about losing control over decisions around their children's care and well-being once they turn 19, and how their children will manage in a world that expects them to be ready to take responsibility for every aspect of their lives.

“I have been able to manage my kids as kids, but I worry about them as adults,” says a mother who has fostered and adopted many children and youth with FASD.

“My adult kids can’t even pay their rent, because they can’t remember, or they see something they want right now and spend their rent money. I don’t know if they’d file income tax. They have no idea what a T4 is. One of my sons is working, but anything that comes in the mail, he just hands straight to me. He doesn’t know a cheque from a bill.”

At the same time, some families told us that this period in their child’s life has also been a time of supports finally coming together. Their child’s adult personality is emerging, and families are better able to see what kinds of supports help the most.

One mother says the transformation in her previously suicidal teenage son was profound once he got the right supports and learning plan at a school designed for youth with his same FASD diagnosis. Another mother noted much improvement in her daughter’s mental health after the family found a school supportive of a learning plan that took the pressure off the young woman.

But this same mother notes that the expectations placed on students in the later grades are designed for typically developing youth, starting with the presumption that every young person ought to be finished with school and ready for independence at age 18 or 19.

“My children have FASD. My kids just need time and space to become who they are,” she says. “But there’s no pathways for people. Why are we trying to make someone fit in the boxes that don’t fit? Why isn’t government front-loading support when they know FASD is over-represented in our prisons? What would they be paying to keep someone in jail compared to the cost of supporting a child to become a healthy individual?”

These years heighten families’ fears about what is coming for their child once they are no longer eligible for CYSN-related services and supports. That’s age 19 for the majority of services.

Another mother who has adult children with FASD is unsettled that so much of her children’s later school experiences left them feeling like failures – coming up short in their academics, failing to fledge into adulthood on schedule. But the real problem is a school system built on neuro-typical expectations and timelines, she says.

The authors of the most recent BCeDAccess *Education Exclusion Tracker Report* highlighted this issue as well.

“Equitable access to education is foundational to a just society. Under the human rights model of disability, we don’t merely accommodate; we ensure that education is accessible, inclusive, and individualized in every location for all students, honouring intersecting identities and considering their impacts,” wrote the report authors.

“It is a collective responsibility and a legal obligation to ensure that all students have this access.”

Here is one mother’s story of dealing with a school system that felt like it was intent on rushing her children out the door.

## Maeve's story

There have been some tough school years for Maeve's three children, all of whom have FASD.

But nothing prepared her for just how hard it would be to go up against an education system fixated on graduating her children at age 18 whether they're ready or not.

Maeve had to fight to slow things down for her young adult son Owen in his final school years, and returned to the same fight on behalf of children Fredrick, age 19, and Lulu, 17.

"In general in our school system, they look at age, not ability," says Maeve. "The system is neuro-typical. They're essentially saying, 'This is where you should be – why aren't you?' It's like blame."

Maeve's children received designations once they were school-age, but the scarce support and requirement for the children to "fit in a box" for services rendered those services largely ineffective.

She has paid out of pocket or sought out charity funding for any other needed resources.

Maeve knows her two youngest children are not ready to leave the structure and learning of high school behind yet: "Our society doesn't readily support young people with FASD to prepare them for career and occupational objectives."

During their time in school, she has routinely bumped up against rules and practices within the education system that disadvantage or even exclude young people with disabilities. Readiness for graduation by age 18 is a striking example of that, she says.

"Sometimes you fall into the trap of thinking that maybe it's true, maybe your kids should have been ready to graduate at age 18. Those are the times when you start feeling you're not good enough, your kids aren't good enough. But it's because the system expects families to push their kids to meet timelines even when they're completely unrealistic for that child."

Such young people are rarely able to access the same opportunities, scholarships and school recognition that are available for other youth in their high school years, especially when those doors close at age 18, adds Maeve. They aren't able to access programs while at secondary school that support a transition to post-secondary and the workplace. "There's no pathways for these kids."

Maeve's wish for her children's schooling has always been a simple one: She wants them to be given the time they need to achieve the same level of readiness and sense of independence that a typical student has by the time they graduate high school.

That may not come at age 18 for a young person with FASD, says Maeve. But the system doesn't bend for young people needing longer timelines.

"You start to feel like you're doing something wrong, trying to find accommodation to get your kid services. Had I known what I know now about how the system works, I wouldn't have pushed my kids to where they were pushed in their earlier years."

Even the month of a student's birthday determines whether they can easily stay on for an extra year of high school.

If a young person turns 19 after July 1 in the year they would normally be graduating, they can re-enroll without difficulty for the following September. But Lulu has a birthday in the first six months of the year, which created a problem for an extended year.

B.C.'s *School Act* states that students with individual education plans and pursuing a Dogwood Certificate "may" continue in school beyond age 19,<sup>24</sup> and may receive all the school-based supports

<sup>24</sup> Section 75(8), B.C. *School Act*

they have been receiving to that point. However, it appears to be the individual school that ultimately makes the call as to whether a student can stay on, says Maeve.

Fighting for a student's right to participate in grad ceremonies is a whole other battle.

Maeve successfully fought for all of her children to walk across the stage with their classmates, but recalls one painful year when she spotted one of her kids' classmates in the audience, excluded from the ceremony after their own family's fight for the same right was arbitrarily denied. "These kids have worked as hard, if not harder, than any other student to reach this point," Maeve notes.

Getting the right school situation for a child makes all the difference, she adds.

"Lulu went through challenging mental health issues in Grade 11 because of the chronological age expectations being placed on her," says Maeve. "We had to do something different for Grade 12. We adapted her workload and she was starting to get the support she needed. We adapted the environment to her, supported her, and she thrived."

Maeve learned her strong advocacy skills from her mother Helen, who is very much an active support for Maeve and her children as well. Both women have lengthy histories of raising children with disabilities, and engaging in the constant advocacy work that unfortunately goes along with that.

But advocacy can feel like a double-edged sword, notes Maeve. Being able to trust the person on the receiving end of advocacy efforts is far from a given.

"So much depends on who you are advocating to, and how much they are prepared to advocate on your behalf," she says.

"It could be I'm talking to the person who wants to find a way to help me – or a reason to close the door. You're afraid of who to open up to. You don't know who to feel safe with. Their level of understanding makes a critical difference as well."

Adulthood brings a new set of worries. Whatever supports a B.C. family has been able to access for their child to that point, there's no guarantee that any of them will continue, says Maeve, even though a disability like FASD is lifelong.

For CLBC supports, Lulu and Fredrick will need to be assessed as having sufficiently low adaptive functions in order to be eligible.

The standard advice to families from people and professionals familiar with the CLBC vetting process is to envisage a worst-case scenario, says Maeve – "like as if you were dropping your kids into Times Square and they have to find their way out." It's a scenario that doesn't capture a child's actual level of need, and ignores their abilities and competencies.

"So many forms, so many questions about adaptive functions. What a person puts on the form would depend on the particular day, the situation, the medications a young person was or wasn't taking," says Maeve.

"And what's the goal, to make the young person look like they're low-adapting? How does the government interpret that – will somebody decide down the line, for instance, that a person isn't fit to be a parent because of that? The adaptive functioning assessment for FASD scares the hell out of me. A lot of days – with the right supports, expectations and understanding – my kids do well."

Like other parents of children and youth with disabilities, Maeve says negotiating B.C.'s systems of social care and the lack of understanding of FASD is far more of a stress than her children's disabilities.

"My kids just need time and space to become who they are. They don't need to fit in the box. But there are no pathways for people who don't fit in the box," she says. "All I want for my kids is for them to be who they want to be, and have the supports to get them there, and keep them there. I don't think it would be that difficult."

## Early Adulthood

RCY's individual and systemic advocacy mandates are primarily focused on children and youth up to age 19 in B.C. However, these mandates extend to young people up to their 27<sup>th</sup> birthdays in certain cases.<sup>25</sup> Improving the experiences of B.C. youth transitioning into adulthood is a key issue for RCY, and we are grateful for the families who shared stories of this difficult transition period.

Just two of the 14 families interviewed for this report have children who are 19 or older. But all of the families with children getting into their later teens are already worrying about what will happen for their child when they turn 19, the age when specialized services end for the majority of children and youth with disabilities in adoptive and biological families.

The transition from youth to adult does not have to be inherently more difficult for a youth with a disability as compared to other young people. What makes this period difficult for CYSN families is that it marks the end of most of the services, equipment coverage, essential therapies and even disability designations that families have relied on for much of their child's life. Comparable services may not even exist for these young adults. Families worry about a future where they are even more on their own in supporting their child.

“A child needs to be able to access services long before critical older years become failures and struggles for these kids, who were born with challenges,” wrote a survey respondent. “Quit shoving parents out of the equation. Listen to them when they say there's a problem, and get them the help they say they need, not what you think they need. My family is a great example of what happens when services don't happen as children.”

All funding for services, supports and therapies through CYSN ends for most of these young people on their 19<sup>th</sup> birthday. Medical benefits for those in the At Home Program end even earlier, at age 18. The early end to At Home Program supports before a youth has even reached age 19 “creates a gap for families that can be really problematic,” says one advocate working in this area.

People with a history in B.C.'s foster care system may continue to receive some supports after age 19. This includes lifelong free tuition and a \$3,500 annual Learning for Future Grant<sup>26</sup> for eligible undergraduate studies at B.C. public post-secondary institutes and for approved union-based trades training for British Columbians who were in care as children or youth for a minimum 24 months. Those who turned 19 while in care are eligible regardless of the time they spent in care.

Youth with histories in care may also be eligible for support through MCFD's Strengthening Abilities and Journeys of Empowerment (SAJE) up to the age of 27, which could include an Agreements with Young Adults (AYA) benefit of up to \$1,250 per month for living expenses and a \$600 a month rent supplement program. However, young people may still need to lean on their families or other supportive adults to assist them in finding and accessing these services.

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<sup>25</sup> This includes young adults who are eligible for CLBC services and who received a reviewable service within 15 months of their 19<sup>th</sup> birthday and young adults with histories in government care who are on or eligible for an AYA or on or eligible for a provincial post-secondary tuition waiver.

<sup>26</sup> <https://studentaidbc.ca/explore/grants-scholarships/learning-future-grant>

A cross-ministry transition protocol for young people with special needs has been in place in B.C. since 2009. But the gap between what the protocol lays out and what actually happens for families can be profound.

Transition planning under the protocol is intended to start at age 14 with a family's CYSN worker taking the lead. But many families report rarely interacting with their workers, virtually all of whom are carrying heavy caseloads. (The 147 CYSN workers across the province carry individual caseloads ranging from 101 to 257.)<sup>27</sup> Some families go for years without even knowing who their MCFD worker is.

As stated earlier, CLBC provides services to very few adults with disabilities. There are currently 27,340 adults in B.C. on the CLBC caseload. That's less than 0.6 per cent of the general population. More than half a million adult British Columbians with disabilities are potentially going without publicly funded supports essential to their well-being.

B.C. launched the Services to Adults with Developmental Disabilities (STADD) navigator program as a pilot in the early 2010s, in partnership with three government ministries, schools, Indigenous Child and Family Service Agencies, CLBC, WorkBC, the Public Guardian and Trustee, health authorities and relevant community groups.

STADD navigators are available only to CLBC-eligible youth and provide services in 145 communities across the province to help youth and their families plan their transition to adulthood, connect to cross-government services and community resources, and develop a "person-centred plan."

Some young people transitioning to adulthood will have the advantage of support and resources from their families to start into post-secondary education and training, or to transition to an independent life with some supports in their own home. Many others will not have such advantages, and will be left completely on their own to figure things out.

Even those who qualify for CLBC services face difficult choices, say families. Young people who qualify for CLBC's home-share program, for instance, may have to leave their communities and move to wherever housing is available. Home Sharing is a shared living arrangement that supports eligible adults to live in the community. It is a residential service in which an eligible adult and a person who is paid to provide support live together in a home that is rented or owned by the paid support person. The home is the primary residence of both the individual receiving supports and the person(s) providing them and can also include an established joint tenancy.

"My children do qualify for home-share, but while it guarantees housing, that's not necessarily in the community where they live," says the mom of young adults with FASD who is featured in our final story.

"So my son could end up moved somewhere else. But he has a job here, community. If you picked him up and put him in some new place with no connection, no one who knew him, that would be a terrible thing for him."

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<sup>27</sup> MCFD Service Delivery Division ADM Estimates Binder 2023.



## Elusive independence

A common outcome for young people with disabilities after age 19 is to be put on income assistance.

Almost three-quarters of British Columbians receiving income assistance are Persons With Disabilities (PWD).<sup>28</sup> A young person or their family will have to do considerable legwork<sup>29</sup> to secure PWD status – especially if the young person has not yet established eligibility for CLBC or was not receiving support through the At Home Program at the time they turned 19.

Benefits of PWD over other forms of income assistance include:

- A higher level of income assistance than regular assistance
- Eligibility for nutritional supplements and other needs
- Medical equipment and other extended medical needs
- An annual earnings exemption of \$15,000 per year for a single recipient without impacting assistance payment<sup>30</sup>
- The opportunity in periods of higher employment earnings to maintain medical coverage by continuing to submit monthly financial reports.

However, one mother notes that household-income rules affecting eligibility for people on income assistance can have a surprise impact on the love life of those with special needs.

She points out that if a young person on PWD moves in with a person whose income is high enough to disqualify their partner from receiving income assistance, that primary income earner is essentially forced into the role of being not only the sole financial support for the couple, but the de facto caregiver for the person with special needs.

“That’s a lot to take on,” she says. “It’s basically a rule that is stopping people with disabilities from getting into a relationship with someone who doesn’t have a disability.”

Another mother is concerned at the typical presumption that every young person is ready for independence at age 19. She knows her son “is not going to be at independence” at age 19.

“So now, it’s looking like we will need to go to court to try to take away his rights to make his own decisions about his life,” she says. “He might be 18, but he shuts down like a seven- or an eight-year-old.”

The strong connections that CYSN families often forge with other families of children and youth with disabilities unfortunately means they are all too aware of what will be coming for them as services drop away in the later teen years.

One mom of a teenager with FASD says she’s observing with horror what is happening for other members of her Facebook-based family network as their own children turn 19.

“I worry about what happens next. CLBC is failing our babies,” she says. “I know four young adults who have totally fallen through the cracks after they turned 19. These kids cannot be independent. Our kids aren’t understood.”

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<sup>28</sup> [https://maytree.com/changing-systems/data-measuring/social-assistance-summaries/british-columbia/#:-:text=On%20average%2C%20there%20were%20just,\(115%2C813\)%20received%20Disability%20Assistance.](https://maytree.com/changing-systems/data-measuring/social-assistance-summaries/british-columbia/#:-:text=On%20average%2C%20there%20were%20just,(115%2C813)%20received%20Disability%20Assistance.)

<sup>29</sup> B.C. has a simplified application process for youth ages 17-19 with a confirmed intellectual disability as well as those eligible for CLBC or At Home Program services.

<sup>30</sup> This will increase to \$16,200 in January 2024.



Another mother says she's witnessing people in her own network "falling off the end of the Earth when their kids turn 19. It's terrifying to watch and disturbing to imagine the same happening to her own family in a few years," she adds.

Years of "having to put your worst foot forward" to get services for a child also weighs heavily on the minds of families, who talked about the pain of having to paint the worst picture of their child's disabilities time and again in order to qualify for services. It is a system that does not allow us to celebrate our children for fear that they will be deemed ineligible for the critical services and supports they need to succeed.

One mother fears that such a deficit-based perspective could come back to haunt her adult children if, say, they want to have their own child one day but, on paper, look incapable of being good parents.

How children are spoken of impacts their perception of themselves. Growing up in a world of deficit-based language can make a person feel like they are always "broken," and mental-health issues are common as a result.

"Why do we always have to talk about our young adults in deficit-based terms?" she asks. "What's making them stronger? Can we talk about that?"

For young adults transitioning from the foster care system, the hard shift into "adulthood" can be disastrous at an age when most young people are still very much dependent on support from their families.

Some will have an academic standing from grade school sufficient for them to be accepted into post-secondary training, with government covering their tuition costs. Since the waiver program was introduced in 2017, some 2,300 young British Columbians with histories in foster care have had a total of \$16.6 million in tuition and fees waived.

Other young people with disabilities will find paid work, though not nearly as easily as young adults without disabilities. Statistics Canada reported an employment rate of 54 per cent for young adults with disabilities ages 15 to 24 in 2022, compared to 64 per cent for those without a disability.<sup>31</sup>

Young adults with complex health needs will continue to receive taxpayer-funded medical care just like any British Columbian. However, they are reliant on their former pediatricians or family doctors to help them transition from the child/youth system to the adult system and in many cases will run up against the ongoing shortage of doctors and specialists.

The challenges for these young people go beyond services and supports. One mother whose son is involved in hockey and skiing programs for young people with FASD says few things are sadder than seeing young people turn out for those programs lacking anyone in their lives beyond someone being paid to support them.

"We've got kids playing hockey who are in a CLBC home share, for instance, and we really need the home share to engage on their behalf," she says. "But they're the workers and they don't feel that urgency.

"Then you've got these young people living on their own with an AYA and someone signed them up for skiing. But how do they get to the mountain? Who do I call when a boy in an AYA ends up with a concussion from skiing and there's nobody to check on him?"

The mother says her heart aches for these young people, who are not only alone in terms of their challenges, but with their successes.

<sup>31</sup> <https://www150.statcan.gc.ca/n1/daily-quotidien/230830/dq230830a-eng.htm>

“Every single person in the whole damn world has to have somebody in their life who lights up to see them. That boy with a concussion? He’s gone from a non-snowboarder to possibly ending up on the provincial team. But who does he share that wonderful news with? Who lights up for him?”

We will close off our 14 family stories with the story of Robin, who shares her farm in northern B.C. with seven teens and young adults who are her foster children, adopted children and home-share clients.

### Robin's story

Robin is a foster mom who keeps hearing from people that there are government services in B.C. for the young people in her care at her rural home in the north of the province. She knows better than to believe it, she says.

Six of the seven teens and young adults who live with her on the farm have FASD, and all have other diagnoses as well. But the only support Robin qualifies for from the province is a bit of respite for the two under age 19 – respite that she has rarely been able to access because of the difficulty finding skilled workers able to handle the high needs of her children.

“Sure, we need services, but who’s going to provide them, and how are we going to get there?” asks Robin. “I’ve tried for a long time to find services. I don’t think they exist.”

Some of the young people living with Robin are her adopted children. Some are foster children. One is in a home-share arrangement, and another is an adult sibling of other young people living there.

It all makes for a busy, buzzy scene around the kitchen stove at dinner on this particular night. But Robin takes it all in stride, having been a foster mom to 39 children and counting over the last 25 years, many of them with FASD.

An FASD diagnosis or suspected diagnosis qualifies a child in B.C. to access a key-worker program intended to help navigate families to services. But when no services exist for families of children and youth with FASD – or when services are available only in urban areas – that’s a major limitation.

Even just securing an FASD assessment is difficult, slow and very expensive if families have to turn to the private system. As Robin knows through her own experiences, supports are scarce to non-existent even with a diagnosis, particularly for families outside of the province’s urban centres.

Robin’s children are First Nations, allowing her to access medical and mental health supports through an Indigenous child and family service agency. The agency stepped in to help her family with immediate needs and funds when the family home burned down in 2019.

“We did finally get a counsellor through them for one of the boys, Richard, who is 15. As a guardian agency, they do as much as they can,” says Robin. “But we are now seeking an autism assessment for Richard, and the provincial wait list is horrendous. We will be advocating for a private assessment.”

The highly individual impact that FASD has on the life of a particular child or youth also complicates service access. The disorder doesn’t fit into the tight eligibility boxes that government has developed around services for children and youth.

The absence of support and lack of awareness across virtually every service system for FASD families can feel especially cruel, says Robin.

She won’t soon forget the many seven-hour roundtrip drives to the nearest big city for medical appointments and various assessments that went wildly sideways when a change of plans or a sudden development set a child off. Time and again, she was left to sort things out with no help in sight and a whole lot of judgment from those unfamiliar with FASD.

"If you don't live it and do it and have the personality for this work, the skillset, whatever, it is really overwhelming," says Robin. "If you don't understand trauma and how that plays out for a child – well, the saying is that the child who needs the most love will ask for it in the most unloving ways."

One boy kicked out Robin's van window on a drive to the city after realizing he had forgotten his wallet at home. Another's unpredictable stress reactions left Robin to do the whole drive with one eye trained on the child via the rear-view mirror, monitoring whether he was working up to an outburst.

Another child, eight at the time, jumped out of her car and bolted down the highway after Robin pulled over to wait out a massive outburst. She called 911 hoping for help, only to be told that because she'd said the small boy was acting violently, police would have to be notified first.

"In the end, nobody could do anything and he wore himself out. So...services???" asks Robin. "I know this all sounds so extreme, but many parents and foster parents live with this all the time. What do you do? You ride it out."

These days, she has other worries as her children grow into adults.

Young people with FASD mature toward independence at slower rates than typical children, and some will never be able to achieve full independence. The expression common in FASD circles is that these young people require an "external brain" – somebody to help them make the right decisions, temper impulsiveness, and stay on top of all the details of life while encouraging independence.

But the systems that drive the world make no accommodation for people who need a little more time and help to function well.

Robin points to some of her young family members who have paid work as examples of this issue. They are valued workers and doing well on the job, but first they needed Robin's support to polish up a resume, coach them how to present at the interview, and understand how to meet an employer's expectations.

She expects they may always need her help to remember to do their taxes, fill out forms and get their bills paid on time. They need a benevolent landlord willing to set up a failsafe arrangement so the rent is paid on time and ensure the tenants understand their rights; Robin recalls rescuing one of her young adults from a freezing-cold apartment where he hadn't known that he had the right to demand more heat.

"I don't see why people with special needs don't just get services. The dividing line between autism and other disabilities, between support for foster parents versus biological parents – what difference does it make?" questions Robin.

"Why all this 'a diagnosis of this gets x, a diagnosis of that gets y'? Biological parents don't qualify for supports they really need. Foster parents do but can't find the services. The money I get doesn't help because I can't use it to access services that don't exist. Money doesn't fix the crises my family experiences."

Robin dreams of building a big lodge for young adults with FASD, one that "did everything from detox to trauma care" and offered a range of therapies, horses, kayaks, and Indigenous mentors and teachers.

"The young people could live there until they were ready to leave and come back whenever they needed," she adds.

Whatever is coming next as the B.C. government reconsiders the CYSN system, many things must change, notes Robin. If legal action on the part of families is necessary to make that happen, she says, then so be it.

"The government typically doesn't change until they really, really have to. All the changes that have come for Indigenous people, for instance, are because government lost court cases. I think that's where we have to go with FASD, and so many other disabilities."

## Conclusion

Major change takes time, but families in B.C. simply can't wait any longer for changes to the CYSN system. It has been five long years since government set out to address an outdated, inequitable and inadequate system of services and supports for families of children and youth with disabilities, but little of substance has changed. Families are still waiting for more of the services their children need, and tens of thousands are still waiting for any services at all.

The poignant stories in this report illustrate the courage and tenacity required of these families and are reminders of just how hard they are having to fight to try to ensure that their child gets the supports they need. RCY heard over and over again from families that it wasn't their child's disability that left them struggling at every turn, it was the endless battle of trying to secure what their child needs to thrive.

Those five years that have passed since government started engagement for CYSN reform in 2018 in fact represent a third of a childhood for the children and youth in these families. A third of a childhood spent waiting for better services that still haven't come, with still another year and a half to wait – and a provincial election to survive – based on the government's current timelines.

The Representative supports the government in its vision for a needs-based CYSN framework – one that reaches all children and youth wherever they live in B.C. and walks alongside families to help them find what they need at every stage of their child's life.

But this plan appears to be stalled at the vision stage. At this point, evaluations in the four FCC pilot regions won't even be completed until January 2025, which raises the spectre of nothing happening for all of 2024 and into the first half of the next year. The tremendous impact of this wait for services on the lives of children and youth with disabilities is simply unacceptable. This issue so desperately requires immediate action.

A plan that reaches across all relevant ministries and government agencies is essential. Families of children and youth with disabilities should not have to deal with multiple ministries, virtually none of which appear to co-ordinate or share processes with any of the others. Families cannot be left to muddle through the confusing, frustrating and immensely time-consuming maze of paperwork, rules, hierarchies and gatekeepers that they face virtually anytime they try to get their child's needs met.

We urge the government to revisit estimates of how many children and youth with disabilities actually need services. B.C. will be setting itself and families up for failure if the presumption is that there is a mere 8,300 additional children/youth requiring services under a needs-based system. The narrow lens of "disability services" needs to be more inclusive of the greater number of young people with lifelong disabilities who need support. That failure will come on the backs of families and their children, who desperately need this next version of CYSN to succeed in helping them get the support they need and have a right to access.

The Representative has made multiple recommendations related to children and youth with disabilities that remain relevant (see appendix). These should be acted upon while the government proceeds with engagement with children and families and the development of a new system of care.

Signs of major problems in the CYSN system have been evident for many years. Evidence is growing that those long-standing problems are increasing the pressure on other systems meant to support children and youth with disabilities, and they are starting to fail, too.

One of the most obvious examples of this can be seen in the rising rates of school exclusions. These exclusions are compromising the future of children and youth at a critical time in their development when they can most benefit from the right supports. The constant and unpredictable disruptions caused by the exclusions are also interfering with families' ability to earn a living. They're violating the principles of equity and inclusion embedded in our human rights laws and international agreements.

What do families want? So little, really.

- They want inclusion and belonging.
- They want their children to grow up with the right supports to help them realize their potential.
- They want to stop having to portray their children in the worst possible light in order to be eligible for services.
- They want to know that services are there when they need them, and that they won't have to fill out even more forms, sit on even more wait lists to get them, and roll out that "squeaky wheel" to try to be heard.
- They want mental health support – for their child, the child's siblings, and themselves.
- They want an end to having to compete with other families at every turn for scarce services.
- They want to know what they're eligible for without having to poll other families to find out what they get.
- They want an end to feeling guilty when they advocate for their child, when all they're doing is trying to meet their child's basic health and social needs.
- They want their children to grow into young adults with a future to look forward to, not left to "fall off a cliff" at age 19, as one parent put it.
- They want government systems that appreciate and welcome the immense expertise that families bring, and policy-makers who truly want to partner with families in building a system that works for them.

These are not grandiose dreams. They are the dreams that any parent has for their child. We ask the B.C. government to hear the urgency in their voices, and to act swiftly and with wisdom, humility and humanity to end this long wait for essential services and supports.

## Appendix

This chart reflects RCY's publicly reported progress on recommendations. Progress since April 2023 is currently being assessed. The next update will be posted to the RCY website by Nov. 22, 2023 at <https://rcybc.ca/reports-and-publications/recommendations/>.

Alone and Afraid: Lessons learned from the ordeal of a child with special needs and his family – Dec. 10, 2018	Ministries Involved	Last Review	Overall Rating
<p><b>Recommendation #1</b> 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.</p> <p>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.</p>	Ministry of Children and Family Development	Third Update	Some Progress
<p><b>Recommendation #2</b> Pending completion of the comprehensive assessment, that MCFD take immediate steps to improve the current accessibility of CYSN services and supports by providing respite within a reasonable period of time, eliminating the need to choose between medical and respite benefits, and monitoring and ensuring follow-up with families not using autism funding.</p>	Ministry of Children and Family Development	Third Update	Some Progress
<p><b>Recommendation #3</b> 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.</p> <p>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.</p>	Ministry of Children and Family Development, Ministry of Health, Ministry of Education and Child Care	Third Update	No Progress (downgraded from Some Progress)
<p><b>Recommendation #4</b> That MCFD ensure its children and youth with special needs training is mandatory for child protection staff.</p> <p>MCFD to ensure that all child protection social workers complete training by April 2020.</p>	Ministry of Children and Family Development	Third Update	Some Progress
<p><b>Recommendation #8</b> 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.</p> <p>Ministry of Education to complete this work by September 2020.</p>	Ministry of Education and Child Care	Third Update	Some Progress

<p><b>Recommendation #10</b> 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.</p> <p>Plan to be developed by April 1, 2020 with implementation to begin immediately thereafter.</p>	Ministry of Health, Ministry of Children and Family Development	Third Update	Some Progress (downgraded from Substantial Progress)
<p><b>Recommendation #11</b> 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.</p> <p>Wait times to be reduced to nine months by Sept. 30, 2019; to six months by Sept. 30, 2020; and to three months by Sept. 30, 2021.</p>	Ministry of Health	Third Update	Some Progress

Caught in the Middle – Nov. 26, 2019	Ministries Involved	Last Review	Overall Rating
<p><b>Recommendation #6</b> As part of the Ministry of Children and Family Development's overhaul of residential services, MCFD to assess the need for residential care and treatment resources across the province to accommodate children with complex needs and to create sufficient resources to meet the assessed need in a timely way.</p> <p>MCFD to complete this work by September 2021.</p>	Ministry of Children and Family Development	Second Update	Some Progress

A Parent's Duty: Government's Obligation to Youth Transitioning into Adulthood – Dec. 15, 2020	Ministries Involved	Last Review	Overall Rating
<p><b>Recommendation #4</b> MCFD should evaluate the current emergency measures in place due to COVID-19 that allow young people to continue to stay in their foster home or staffed residential placements past their 19th birthday. Our Office anticipates that such an evaluation would reveal benefits and feasibility on an ongoing basis. If that is the case, the ministry should implement changes that would allow for continuing foster home or staffed residential care on a voluntary basis, with the length of extension based on the young person's readiness to transition out of care. Priority consideration should be given to youth and young adults who have disabilities and other physical and mental health needs who are not ready for independence at 19, and not eligible for Community Living BC services.</p> <p>MCFD is to complete the evaluation by December 31, 2021 and develop and implement an approved plan of next steps by April 1, 2022.</p>	Ministry of Children and Family Development	First Update	Complete



Excluded: Increasing Understanding, Support, and Inclusion for Children with FASD and their Families – April 15, 2021	Ministries Involved	Last Review	Overall Rating
<p><b>Recommendation #1</b> 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.</p> <p>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.</p>	Ministry of Children and Family Development	First Update	No Progress
<p><b>Recommendation #2</b> Pending full implementation of 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.</p> <p>MCFD to secure immediate funding enhancements and begin implementation of the expanded eligibility criteria by Sept. 30, 2021.</p>	Ministry of Children and Family Development	First Update	No Progress
<p><b>Recommendation #3</b> MCFD to complete a comprehensive review of evidence-based and promising practices specific to serving children and youth with FASD, including from the Key Worker Parent Support Program (KWPSP), for integration into the CYSN framework. In the meantime, MCFD to take immediate action to ensure that the KWPSP has consistent quality service across all regions of B.C. and is accessible to all families of children and youth with FASD.</p> <p>MCFD to take immediate action to ensure equitability and accessibility of the KWPSP by Sept. 30, 2021 and complete the best practice review by March 30, 2022.</p>	Ministry of Children and Family Development	First Update	No Progress

<p><b>Recommendation #4</b> 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. 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.</p> <p>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.</p>	Ministry of Children and Family Development	First Update	No Progress
<p><b>Recommendation #5</b> 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.</p> <p>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.</p>	Ministry of Mental Health and Addictions, Ministry of Children and Family Development, Ministry of Health	First Update	No Progress
<p><b>Recommendation #6</b> 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.</p> <p>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.</p>	Ministry of Health	First Update	No Progress
<p><b>Recommendation #7</b> That the Ministry of Health, in collaboration with the First Nations Health Authority and with guidance from the Task Team formed as a result of the <i>In Plain Sight</i> report, apply learnings from the review of systemic bias to referral pathways and assessment processes for CDBC diagnostic clinics. The changes/improvements should specifically address the issue of bias with regard to the referrals of First Nations, Métis, Inuit and Urban Indigenous children and youth for FASD assessments and ASD assessments.</p> <p>Ministry of Health to complete the review and implement recommended improvements by March 31, 2022.</p>	Ministry of Health	First Update	Some Progress

<p><b>Recommendation #8</b> 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.</p> <p>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.</p>	Ministry of Health	First Update	Some Progress
<p><b>Recommendation #9</b> 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 DAAs, 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.</p> <p>The cross-ministry plan to be completed and implemented by April 1, 2022 and fully implemented by March 31, 2024.</p>	Ministry of Children and Family Development, Ministry of Citizens' Services, Ministry of Health, Ministry of Mental Health and Addictions, Ministry of Social Development and Poverty Reduction, Ministry of Education and Child Care	First Update	No Progress
<p><b>Recommendation #10</b> 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.</p> <p>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.</p>	Ministry of Education and Child Care	First Update	Some Progress
<p><b>Recommendation #11</b> 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.</p> <p>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.</p>	Ministry of Education and Child Care	First Update	Substantial Progress

<b>Toward Inclusion: The need to improve access to mental health services for children and youth with neurodevelopmental conditions – April 5, 2023</b>	<b>Ministries Involved</b>	<b>Last Review</b>	<b>Overall Rating</b>
<p><b>Recommendation #1</b> 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.</p> <p>Final engagement report to be completed by October 2024.</p>	Ministry of Children and Family Development	Assessment due June 2024	<b>Not yet rated</b>
<p><b>Recommendation #2</b> MCFD to 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.</p> <p>Final evaluation report to be completed by March 31, 2025.</p>	Ministry of Children and Family Development	Assessment due June 2024	<b>Not yet rated</b>
<p><b>Recommendation #3</b> 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.</p> <p>Implementation to begin in April 2025.</p>	Ministry of Children and Family Development	Assessment due June 2024	<b>Not yet rated</b>
<p><b>Recommendation #4</b> 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.</p> <p>Research to begin by April 2024.</p>	Ministry of Children and Family Development	Assessment due June 2024	<b>Not yet rated</b>
<p><b>Recommendation #5</b> 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.</p>	Ministry of Citizens' Services, Ministry of Children and Family Development, Ministry of Health, Ministry of Social Development and Poverty Reduction, Ministry of Education and Child Care	Assessment due June 2024	<b>Not yet rated</b>

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