

# Left Out: Children and youth with special needs in the pandemic

December 2020



REPRESENTATIVE FOR  
CHILDREN AND YOUTH





Dec. 3, 2020

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

Dear Mr. Speaker,

I have the honour of submitting the report *Left Out: Children and youth with special needs in the pandemic* to the Legislative Assembly of British Columbia.

This special report is prepared in accordance with Section 20 of the *Representative for Children and Youth Act*.

Sincerely,



Dr. Jennifer Charlesworth  
Representative for Children and Youth

pc: Kate Ryan-Lloyd  
Clerk of the Legislative Assembly  
Susan Sourial  
Committee Clerk, Legislative Assembly

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

- Aboriginal Infant Development Programs
- Aboriginal Supported Child Development
- ACT - Autism Community Training
- B.C. Child Advocacy Coalition
- BCEd Access
- B.C. Association for Child Development and Intervention
- B.C. Parents of Complex Kids
- Family Support Institute of B.C.
- Federation of Community Social Services of BC
- First Call: BC Child and Youth Advocacy Coalition
- First Nations Leadership Council
- Inclusion BC

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## Executive summary

The COVID-19 pandemic has revealed the fragility of our support systems for children and youth, exacerbating long-standing problems and layering on new ones. For the tens of thousands of B.C. families who rely on supports and services for children and youth with special needs, the pandemic illuminated a crisis decades in the making.

B.C.'s Child and Youth with Special Needs (CYSN) program provides supports up to age 19 across a spectrum of lifelong disabilities, neurological conditions and chronic health concerns collectively known as "special needs." The Office of the Representative for Children and Youth (RCY) has been tracking advocacy requests and critical injury and death reports since the beginning of the pandemic for indications of a COVID-19 connection for families receiving CYSN services.

Concerned about the issues and trends we were seeing, our Office consulted over the summer and fall with families, family networks and community advocacy organizations in B.C. to understand the complex impact of the pandemic on these families. This report tells that story, as well as the ongoing and deeply unsettling story of a piecemeal system that has never provided adequate and equitable support.

Like so many other British Columbians, CYSN family members and caregivers struggled in the early months of the pandemic with the abrupt disappearance of health, social and educational supports for their children and youth. COVID-19-related closures and physical distancing measures have significantly impacted these families and their children, many of whom lost vital medical treatments, therapies, specialized recreational activities and respite.

These families continue to struggle. They have faced difficult questions around whether to send a child with complex health issues back to school, and have struggled to access services in a time when processes continue to be disrupted. Meanwhile, the extra support and flexibility in services provided to families in the first months of the pandemic ended at the end of September.

As our Office began to explore the impact of the pandemic on these families, it became obvious that this report would be as much about historically inadequate CYSN supports as it would be about the impact of COVID-19. It's not possible to separate the pandemic's impact on CYSN services from the reality of services that have been desperately thin and inequitable since long before the pandemic.

The lack of equity in how CYSN families are served in B.C. is a source of tremendous frustration for families and our Community Partners. Many families of children and youth with special needs aren't able to access any supports, because their children's needs or diagnoses do not meet CYSN eligibility criteria. The criteria exclude children and youth with fetal alcohol spectrum disorder (FASD), attention deficit hyperactivity disorder and complex behavioural needs.

This report builds on a solid foundation of advocacy that B.C. community organizations and families have been tirelessly engaged in for many years. We are indebted to these advocates for sharing their wisdom and experience with us in four consultations this summer and fall, and have drawn on the numerous family surveys and reports that these Community Partners undertook in the first months of the pandemic.

## Executive summary

Building off these surveys, we conducted our own survey in November 2020, with responses from 545 families of children and youth with special needs, representing rural and urban families from each region of the province and including families of First Nations, Métis and Inuit children. The intention of the survey was to provide families who are continuing to live through the pandemic with their children an opportunity to identify ongoing impacts, given that the initial surveys conducted by our Community Partners were from April 2020. It was not intended as a scientific instrument, but rather, as an instrument that would allow us to quickly hear from families most impacted. The fact that the survey was only live for three days and we received such a substantial response is telling of how desperate these families are to share their experiences and to be heard.

We also talked with 10 CYSN families from all over B.C. who reached out to RCY to talk about life in a pandemic. Their moving stories are shared throughout this report. Their powerful accounts of trying to hold things together during unprecedented crises illustrate the urgency of taking action to provide more support to CYSN families.

In consultation with our Community Partners, eight points for immediate government action have been identified:

- Rapidly develop and roll out a family-engaged, plain-language communication strategy in the Ministry of Children and Family Development modelled on the family-engaged model used by Community Living BC throughout the pandemic.
- Extend for one year (Fall 2021) all pandemic-related benefits and processes for CYSN families.
- Create a roundtable that brings together designated representatives of CYSN family networks, advocacy groups, community service providers and funding ministries for regular and routine check-ins and brainstorming on emerging needs, barriers to services and access to supports. The work of B.C.'s Social Services Roundtable provides a model. This body must include Indigenous organizations and communities to prioritize the wellness of First Nations, Métis, Inuit and Urban Indigenous children in B.C.
- Declare CYSN families essential workers for the purposes of allowing them to access critically important services during pandemic lockdowns.
- Work with and fund community organizations that serve CYSN families to develop activity plans for children losing school- and community-based services.
- Review virtual service provision of child development services to CYSN families during the pandemic's first wave to identify promising practices and weak points for improvement.
- Streamline approval processes for all CYSN funding streams and emergency benefits, with an objective of reducing paperwork for families and confirming that all approval processes are viable even during the mass disruption of a pandemic.
- Collaborate with community public health officials to explore whether "bubbles" can be created for in-home services such as Nursing Support Services and respite so that families and providers can limit their exposure to others during a pandemic.



These measures will help CYSN families in the short term. However, they will not fix a system that in some cases has not adjusted support levels in 30 years. They will not fix the unfairness of a system that does not consider a child's actual needs when deciding what supports they will receive. They will not fix a system that leaves uncounted thousands of B.C. children and youth with special needs with no services whatsoever, solely because they don't fit into the right boxes for eligibility.

That, too, is work that must begin now. It should have begun decades ago. The Representative strongly urges an immediate re-engagement of Community Partners on the design, development and implementation strategy for the new CYSN framework.

The Representative and Community Partners cannot imagine any British Columbian not being moved by the stories and concerns shared here. We look forward to an engaged, informed and family-centred response from government that will ensure vital supports for families and community organizations and a better future for the B.C. children and youth who are counting on all of us for humane, equitable and needs-based supports.

## Introduction

The coronavirus pandemic has led to unprecedented disruption in every system, service and support in British Columbia. The impact has been most profound in areas that were already fragile and fractured before the pandemic. This has been the case for the tens of thousands of B.C. families who rely on supports and services provided to children and youth with special needs through the Ministries of Children and Family Development, Education and Health.

Within the Ministry of Children and Family Development, the Children and Youth with Special Needs (CYSN) program provides supports to children with a wide spectrum of lifelong disabilities, neurodevelopmental conditions and chronic health concerns, collectively known as “special needs.”

B.C. families and the community organizations, advocates and family networks that support them have been raising the alarm for 20 years about major problems in supports and services for children and youth with special needs. The Representative for Children and Youth [RCY] echoed this in the release of the 2018 report *Alone and Afraid: Lessons learned from the ordeal of a child with special needs and his family*, detailing heart-wrenching systemic failures in supporting a young First Nations boy with special needs.

The B.C. government immediately adopted all 11 recommendations from *Alone and Afraid*, including the following:

1. That MCFD undertake a comprehensive assessment of the actual need for CYSN services across B.C. and the capacity of the current system to meet those needs. This assessment to examine funding, staffing levels and workloads, program delivery and wait times. Findings to be used to inform comprehensive service improvements so all eligible children with special needs and their families receive culturally respectful, appropriate and timely services and supports. MCFD to complete the comprehensive assessment and plan by the fall of 2019, seek necessary funding enhancements and begin implementation of changes by April 2020.
2. 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.

Government has made some progress on the recommendations, but they are still awaiting implementation.<sup>1</sup> According to our recommendation, MCFD was to have had a comprehensive plan in place by fall 2019, and to have sought necessary funding by April 2020. That has not happened. To date, a draft framework has been produced with no specific action plan and no evidence of new funding on the horizon. The COVID-19 pandemic has further revealed the deep inadequacies, inequities and frailties of CYSN services.

The observations brought together in this report represent the experiences of our Community Partners and CYSN families in the first eight months of the pandemic. Some of the challenges they encountered

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<sup>1</sup> RCY has developed a streamlined process to track recommendations, the results of which are posted publicly. For an update on recommendations from *Alone and Afraid*, please refer to the RCY website: [https://rcybc.ca/wp-content/uploads/2020/04/Alone.and\\_.Afraid.RecsPost.FINAL\\_.April\\_.20.pdf](https://rcybc.ca/wp-content/uploads/2020/04/Alone.and_.Afraid.RecsPost.FINAL_.April_.20.pdf).

The Representative notes that government did increase respite funding by \$6.3 million in July 2019 to reduce the wait list for support.

in the initial months have evolved: modified in-class learning has resumed and some in-person community services and supports are available again. But life is far from being back to normal for CYSN families as the pandemic continues.

Through our advocacy work, connections to families and caregivers and to the organizations that support them, RCY sees that families are committed advocates for their children with special needs. However, it is the Representative's view that many families and caregivers are reaching the breaking point. The disruption of the pandemic continues to reverberate in the lives of CYSN families. The suspension of in-class learning in the spring and the closure of community services providing therapies and supports restricted access to essential health care services. Other services moved online. Collectively, those measures have taken an extraordinary toll on children and youth with special needs across the spectrum of those needs, as was confirmed by the hundreds of families who responded to a November 2020 survey RCY conducted.

The RCY Advocacy and Reviews and Investigations teams have been tracking advocacy requests and critical injury and death reports since the beginning of the pandemic for indications of a COVID-19 connection. We have seen CYSN family members and caregivers struggling with the abrupt disappearance of health, social and educational supports for their children and youth; a lack of information; and inequitable access to the few supports that have been available. While educational supports did continue for children of essential workers, students who require additional supports and students with disabilities, families and Community Partners informed us that communication was not clear.<sup>2</sup> As our November survey confirms, many remain fearful of putting their children into an environment where COVID-19 transmission is possible.

Community advocacy organizations and networks in B.C. that work closely with children and youth with special needs and their families have repeatedly expressed their alarm at the pervasive impact of the pandemic since March. The work of those groups in gathering information and feedback from family members and caregivers to present to decision-makers provides the foundation for this report. These advocates have written letters, brought forward requests, offered solutions and filed complaints with the Ministry of Children and Family Development related to the lack of an effective government response to the challenges facing children, youth and families impacted by COVID-19.

Aware of the concerns of the CYSN community, the Representative hosted three virtual gatherings over the summer with Community Partners and a fourth during the fall. Through their direct advocacy work, these partners have offered their knowledge and experience to inform effective pandemic emergency responses that would support CYSN families.

Those virtual gatherings included representatives from Aboriginal Infant Development Programs; Aboriginal Supported Child Development (both AIDP and ASCD are hosted by the BC Association of Aboriginal Friendship Centres); ACT – Autism Community Training; BCEdAccess; BC Association for Child Development and Intervention; B.C. Parents of Complex Kids; Family Support Institute of BC; First Call: BC Child Advocacy Coalition; Inclusion BC; and the Federation of Community Social Services of BC. A First Nations Leadership Council representative was also engaged.

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<sup>2</sup> Ministry of Education, "Five Stages Framework for K-12 Education," B.C.'s Back to School Plan, last modified July 29, 2020, <https://www2.gov.bc.ca/gov/content/education-training/k-12/covid-19-return-to-school/five-stages-framework>.

## Introduction

At the request of RCY, these groups put out a call for families willing to talk to our Office about their experiences in the pandemic. This allowed us to connect with 10 families from diverse backgrounds whose powerful stories are documented in this report. We are deeply grateful to these organizations and families for sharing their unflagging passion, insights and experiences for the purpose of this report. We recognize that the time constraints of a rapid-response report limited our ability to capture the diversity of experiences for CYSN families. As well, we have drawn on RCY's COVID-19-related data, the *Alone and Afraid* report and a number of family surveys and reports produced by these Community Partners.

RCY undertook this report to bring government's attention once again to the critical issues of struggling, overwhelmed B.C. families of children and youth with special needs. The report is focused on the impact of the pandemic, but it is not possible to tell that story without exploring the fundamental problems and insufficient resources that have been commonplace in CYSN services for more than 20 years. CYSN workers carry this burden, dealing with scarce resources in a fractured system while carrying unmanageably high caseloads. Our Office acknowledges their efforts in the face of very challenging circumstances.

### Report Limitations

#### Engaging newcomers

Surveys have been in English, which is a missed opportunity to hear from what many service providers consider to be B.C.'s most marginalized families of children and youth with special needs in the province. In research detailing chronic health disparities among refugee and immigrant children in Canada, it is recognized that these children are vulnerable to health disparities because of their families' social and economic conditions related to poverty and social marginalization, and poor access to the inter-related systems of health, economic and social resources.<sup>3</sup>

#### 2SLGBTQIA

RCY did not engage specifically with families with 2SLGBTQQIA children and youth with special needs. This has limited our ability to provide more detailed information on how services and practitioners could be more informed on their needs. However our survey results highlighted the need for services and practitioners to be informed on the needs of 2SLGBTQQIA children and youth with special needs.

#### Families who aren't receiving CYSN services

There is no data on how many B.C. families have children with special needs. As of March 2020, MCFD indicated there were 2,672 families deemed eligible for CYSN Family Support Services. These families were approved for a specific service but were not yet receiving services. Many families receive publicly funded services, but we don't know how many families require similar services. These families, including families of children and youth with FASD, are largely invisible for the purposes of data collection. Our November 2020 survey of 545 families included 76 respondents (14 per cent) who have children and youth with special needs but are not receiving any CYSN services.

<sup>3</sup> G. Lane, M. Farag, J. White, C. Nisbet and H. Vatanparast, "Chronic health disparities among refugee and immigrant children in Canada," *Applied physiology, nutrition, and metabolism*, 43 (10), 2018.

## Family story: Renata, Marco and Dylan

March 30, 2020 will go down in the books for a northeastern B.C. Métis family as the day that their teenage son's life exploded.

Concern about the pandemic had been building in B.C. for a couple of weeks before that, and a state of emergency had been declared. But for 15-year-old Dylan, reality sunk in on the day he was supposed to be returning to school after spring break.<sup>4</sup> For a boy with autism who really counts on his routines and daily activities, that was devastating.

*“The impact of COVID was instant for him,” says his mother Renata. “His whole world just ended. Behaviour challenges came out. His entire routine and life had been turned upside down.”*

The family has been in full-on crisis ever since, and in November had to make “an emergency move” to the Lower Mainland and temporarily put Dylan in government care to get him the help he needs, says Renata. Up to the start of the pandemic, Dylan had “a very full schedule” of school, several youth groups and a boys’ group. The family was in the process of re-establishing visits to the specialized activity rooms and equipment at the community child development centre, and had day camps all summer long. The loss of it enraged Dylan, and he began refusing to come home.

He would disappear within the community for days at a time, while his worried parents called the police. MCFD social workers were fielding calls from the teen, who told them he didn’t feel safe at home. He ended up under a voluntary care agreement for a month and spent 30 days in a respite facility. Dylan is back home now, but there’s still no change for him, says Renata.

*“The minimal support we were getting before the pandemic was just barely able to help. Well, COVID took it to zero,” she says. “Normally Dylan would have been in school until the end of June, would have gone to two summer camps, gone to day camps through the development centre. None of that happened for him this year.”*

The family’s three-year-old son Joel has also been profoundly affected by the social isolation of the pandemic – and Dylan’s increasingly aggressive behaviours. The toddler got wired up to the point where his parents were having to load him into the car every day so he’d sleep for a while.

Renata and husband Marco decided to make lemonade out of lemons: Renata found work as a private contracted food delivery driver after the pandemic started with assistance from Marco, so they could earn a little money while Joel napped.

The family initially didn’t qualify for the special pandemic benefit for B.C. families of children with special needs, available only to families who were on the wait list for respite services. (The benefit was later offered when Dylan’s Voluntary Care Agreement ended.) But what really irked Renata and Marco was to have money from the provincial government sitting in a special autism account that the family manages, but that they couldn’t use because they weren’t able to access the necessary approvals.

Families of B.C. children ages six to 18 with an autism diagnosis are eligible to receive up to \$6,000 a year through the province’s autism funding portal. At the start of the pandemic, government raised

<sup>4</sup> Names have been changed.

the limits for spending on equipment needs from 20 per cent to 35 per cent of total funding – a move that recognized that children like Dylan would need more things to do at home.

*“There’s no summer camps, no day camps, limited activities. These are kids stuck at home,” says Renata. “At the very least, they need sensory stuff to distract them – a trampoline, for instance, or a hammock so there’s a place to chill out in the backyard. For Dylan, maybe a punching bag so he wouldn’t take it all out on me. They need all those tools that the development centres usually provide to them.”*

Unfortunately, the family didn’t know that MCFD temporarily suspended the requirement of a form signed by a designated health professional justifying why a particular child needs a specific piece of equipment. With CYSN social workers and health professionals distracted by many other emergencies during a pandemic, they looked in vain for a professional to sign off on the “Justification for Equipment” form.

That left the family with “a bank account full of money” that they didn’t know they could spend, and fearing a fast-approaching deadline to either spend it or lose it.

*“Just let us use that money!” says Renata. “I think there would be families like ours who would be so happy to use it even for housekeeping because they’ve been with their kids 24-hours a day and nothing else is getting done.”*

Delays of many months to be approved for a piece of equipment are difficult at the best of times, says Renata. They’re downright disastrous in a pandemic, when children’s needs are critical and immediate.

*“First you do the paperwork, then mail things back and forth, and the next thing you know, it’s six months on and the whole point of needing that piece of equipment is lost,” she says.*

*“If we’re going to be in this COVID thing for a while, how about government puts out a list of things that families like ours can get without having to go through the justification? How about they approve us to buy a GPS system? We know a lot of families of kids with autism who are having problems with their kids bolting, and right now all we can do is call the police and say, ‘Our son’s gone missing again.’”*

Witnessing their son’s crisis during the pandemic has left Renata and Marco dreading Dylan’s 19th birthday, when his family no longer has the legal right to help him with his life. They know he won’t be ready for adult life, and worry for his safety.

The loss of therapies and activities for children with autism because of COVID-19 has created “a black hole” year for their families, notes Renata. Autism funding ends when a child turns 18. Families with teenagers are losing months of support for their children at a time when there aren’t that many more months of it left, she says.

*“There’s no way to band-aid this for families,” Renata adds. “If families could get what they need, that would be the difference.”*

All impacts of the pandemic disproportionately affected the one-in-five B.C. families that live in poverty, who in turn are disproportionately Indigenous, racialized or new to Canada, or led by single mothers.<sup>5</sup> Our Community Partners tell us that the long-standing scarcity of both respite providers and the money to pay for them in B.C. impacts most heavily on these vulnerable families.

Particularly powerful was the fear expressed by some families that they would have to put their child into government care just to get them the services they need to be safe or sufficiently supported. Indeed, children and youth with special needs who are in government care do receive more funded services than those who remain in the family home.

*“There’s no support for building family resilience,”* said one Community Partner.

“Since I am a single parent, during COVID my son’s father has not been able to see him, resulting in me having absolutely no break from him outside of school hours. I am not able to take him shopping, or organize respite beyond one or two people, which means I am always working or with my son and juggling my other responsibilities. I never have a moment to myself, and am in desperate need.”

– from RCY November 2020 survey

## The instant impact of the pandemic

No government anywhere in the world has had experience with a global pandemic, and we recognize that the B.C. government is having to manage the diverse concerns of virtually every sector and a hard-hit economy. B.C. is not alone in struggling to know how best to support families in these unprecedented times. That said, there is no question that chronically scarce CYSN supports have become even scarcer as a result of the pandemic.

Funding approval processes requiring families to first secure the approval of a professional fell apart because few professionals were available. Contact with CYSN workers and other health professionals that families require for the health and well-being of their children became even more difficult as MCFD transitioned to virtual service delivery and dealt with high call volumes. Our November 2020 survey of 545 CYSN families found that 45 per cent of respondents had no contact with their CYSN worker during the six months (April to September) when emergency measures were in place, and 63 per cent report no contact since measures ended.

Community Partners say MCFD’s management of CYSN services during the pandemic has been flawed. A CYSN virtual town hall was held April 3 by MCFD and the ministries of Education and Health, but our partners describe a lack of meaningful communication beyond that, and a failure to accept their recommendations to take action to help medically fragile CYSN children and youth through monthly support payments, early introduction of the Child Opportunity Benefit, and financial support for the many B.C. families of children and youth with special needs who currently receive no CYSN services.<sup>6</sup> In contrast between April 1 and the end of September, CLBC issued 27 weekly news bulletins, hosted seven teleconferences and invited families to sign up for regular email updates. MCFD acknowledges a limitation of its system is an inability to communicate directly with families of children and youth with special needs.

<sup>5</sup> B.C. Child Poverty Report Card 2019, First Call: BC Child and Youth Advocacy Coalition, Jan. 14, 2020, <https://firstcallbc.org/news/2019-child-poverty-report-card/#:~:text=Overall%2C%20BC%20had%20the%208th,%2Dparent%20families%20is%2051.4%25.>

<sup>6</sup> The Child Opportunity Benefit is a tax-free monthly payment to B.C. families with children under age 18 and came into effect Oct. 1, 2020, <https://www2.gov.bc.ca/gov/content/family-social-supports/family-benefits/child-opportunity-benefit.>

## Introduction

“I am so grateful that I could use this funding for housekeeping. At first I thought it was just a nice thing but it’s made a significant impact on our family. The energy is calmer, we eat together at the table more often and I have more time to spend with my kids. It has been the biggest gift and I pray it will be continued after the emergency ends.”

– from RCY November 2020 survey

*“The government needs to recognize the enormous toll an abrupt loss of complete supports has on my family and mental health, and how desperate I became for help,”* wrote a respondent from a Northern rural community in our November 2020 survey. *“A caregiver’s mental health is just as important as the well-being and therapy for the special needs child.”*

As well, the lack of support has left some families struggling to manage on their own with children whose severe behaviours have deteriorated in the pandemic, which can threaten the child’s safety as well as that of their siblings and parents.<sup>7</sup>

A few aspects of the provincial and federal pandemic response benefited CYSN families, and will be important to build on as the pandemic continues. One B.C. mother – a seasoned advocate for her six-year-old son – says she felt ever so slightly heard for the first time.

*“We’ve been at this group advocacy for many years now, but it was like in the rush of life, no one could hear our voices until now,”* she says. Even so, *“it feels like we aren’t quite being heard.”*

However, responses to our November 2020 survey confirm that chronic communication issues with CYSN workers interfered with families’ ability to access services or even know that they existed. More than 22 per cent of families report they still have not been able to access any CYSN emergency benefits. Eight months into the pandemic – and at a time when almost all CYSN emergency measures have already ended – 60 per cent say they’re still trying to find out what they are eligible for, a response that underlines the breakdown in communications with families.

The federal Canada Emergency Response Benefit (CERB) was a major relief for some families, as was increased flexibility around how families could use respite funding. Community Partners and families were appreciative as well of higher allowances for equipment purchases for families on the autism program, although this allowance was rescinded by MCFD on Sept. 1. A third of the families responding to our November 2020 survey have received CERB during the pandemic, and 46 per cent said that MCFD allowing increased flexibility of respite funding was useful for their family.

*“We weren’t told about the increase to the 35 per cent for equipment with autism funds until five days before it ended, which wasn’t enough time for us to utilize it,”* noted one family in the November 2020 survey.

The importance of connections and relationship is now vividly clear. Some families tell of CYSN workers who went out of their way to help them in the early months of the pandemic, and to find out what emergency benefits they were eligible for. One family’s school principal came around once a week with a bag of takeout.

Another family gratefully received more occupational therapy time than in pre-pandemic days when their therapist made an extended effort to deliver services via Zoom. Their local child development centre brought over toys and equipment to help their son with autism in the months when he couldn’t access the specialized rooms at the centre.

<sup>7</sup> This is anecdotal information from families and Community Partners. The number of Special Needs Agreements with MCFD has not increased since the start of the pandemic.



But where relationships hadn't already existed or where CYSN workers were overwhelmed with competing demands for already scarce resources and high caseloads, many families felt alone. *"Please, better communication all around!"* wrote one respondent in the November 2020 survey. *"I only hear about any of this from Facebook groups. I don't know what my son qualifies for, and Facebook shouldn't be where I look it up."* Community Partners also report a falling away of professional relationships and important communication pathways that they'd worked with government to create in the months before COVID-19.

CYSN families count on charities to fill in funding gaps for equipment needs, but the combination of the pandemic and unprecedented requests for help have overwhelmed one of the most prominent B.C. charities. Variety The Children's Charity stopped accepting all grant applications in the first months of the pandemic, and for an additional period was accepting applications only for tuition, tutoring or the purchase of continuous glucose monitoring equipment.<sup>8</sup> Last year, Variety funded \$3 million worth of orthotics, mobility devices, occupational therapy, education supports and more for almost 4,400 B.C. children with special needs.

*"The grants have become smaller in the last couple of years as demand went up and Variety tried to help more people,"* says a mother of two teenagers with fetal alcohol spectrum disorder (FASD) who now face losing the specialized counselling that Variety grants have helped the family with for years. *"We don't receive any CYSN support, so I don't know what we're going to do."*

The bureaucracy that is a fact of life for CYSN families has taken on a darker tone in the pandemic. An example: this email (edited by RCY to eliminate identifying information) from an MCFD worker – presumably overwhelmed by time demands and scarce resources – sent to the low-income parent of a young child with complex needs who requires medically necessary equipment to prevent further deterioration of the child's leg muscles and hip joints:<sup>9</sup>

"Many children have lost valuable ground in their development, with regression and mental health issues. It can take months and months to regain these skills."

– from RCY November 2020 survey

*The stander got approved, you should receive a letter in the mail. They approved \$2,025 because they think you have a table and a base out. I have called and tried to sort this out, and the table was found, so this money should go back in the "pot." I cannot track the base down so unfortunately this comes out of your Alternate Positioning pot.*

*The standing frame is \$4,753, so now we have to find some funding. [The other worker] and I will look into this. I am not overly optimistic, as most sources are buckling down during the pandemic. We will continue to work on this until your file is transferred to the schools.*

As previously noted, the impact of the pandemic disproportionately affected CYSN families who are also Indigenous and Black, families of colour, newcomers and refugees, along with low-income and single-parent families. Thirteen per cent of respondents in our November 2020 survey identified their child as First Nations, Métis or Inuit. Despite Jordan's Principle, First Nations, Métis and Inuit families can often get lost in the ongoing jurisdictional conflicts with provincial and federal funding obligations. CYSN is already complex and hard to navigate for families who speak English and were born in Canada. For families who are new to Canada or where English is not their primary language, this is a huge barrier.

<sup>8</sup> Variety The Children's Charity, "Grants," n.d., <https://www.variety.bc.ca/grants/>.

<sup>9</sup> Received in August 2020.

## Introduction

Many of these families fear government, which constitutes an additional barrier. Across every category, women bear the brunt of the lack of care and supports due to their role as primary caregivers, our Community Partners told us.

The impact of the pandemic on every B.C. child and youth is incalculable. Calls to the *Kids Help Phone* from B.C. children rose by 70 per cent during the first months of the pandemic.<sup>10</sup> At a time when many CYSN families were experiencing less support than ever, thousands of children with special needs missed essential medical appointments and had their therapies, services and routines come to an abrupt end – in some cases, for six months or more. The suspension of scheduled surgeries due to COVID-19 led to the cancellation of 7,600 pediatric surgeries across Canada from mid-March through June, while another 4,000 surgeries went unbooked. The majority of those surgeries involved children with complex health needs.<sup>11</sup>

Community Partners told RCY of struggling to get information from government to help support desperate families. Regional contacts within government in many cases knew nothing about the pandemic-related supports designated for families, or who was eligible for them. Programs in which families self-direct their funding experienced major problems when approval processes broke down.<sup>12</sup> These approval processes had not been appropriately adapted to take into account circumstances of COVID-19. *“The inconsistency is wild,”* noted a respondent in the November 2020 survey. *“I would not have known anything without being part of parent groups. Even when we KNEW that receipting and tracking was not required, it was still required by my CYSN worker.”*

In an April 2020 survey of 1,055 B.C. families of children and youth with special needs, nearly 70 per cent of families eligible for respite funding reported being unable to use their funding as the pandemic took hold.<sup>13</sup> Almost 60 per cent of responding families couldn't access any of the pandemic emergency supports developed by MCFD. RCY's November survey found that access to emergency supports had improved for some families, but 31 per cent still reported that they had not been able to access any supports. Fifty-five per cent of families eligible for respite funding still have not been able to make use of that funding.

The Provincial Health Officer and the Ministry of Health both emphasized the importance of protecting medically fragile populations in the pandemic. But Community Partners say that CYSN families appeared to be a low priority for MCFD. *“When the rubber hit the road, CYSN were a footnote,”* noted one.

Many services for children with special needs are delivered through the school system. The suspension of in-class learning this spring disrupted their education and ability to access even the limited school-based therapy programs that are usually available, say our partners.

When the province directed schools to reopen and focus on children who would benefit from extra supports, school districts interpreted this in different ways. Some were unable to provide the necessary

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<sup>10</sup> “Kids Help Phone reports spike in calls from B.C. children during COVID-19,” *CBC*, July 14, 2020.

<sup>11</sup> Erik D. Skarsgard, “Prioritizing specialized children’s surgery in Canada during the COVID-19 pandemic,” *Canadian Medical Association Journal* 192, 41 (October 2020).

<sup>12</sup> Autism program requires families to [hire/manage their own service providers](https://www2.gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/special-needs/autism-spectrum-disorder/build-your-support-team/hire-manage-service-providers) and get sign-off on equipment purchases, <https://www2.gov.bc.ca/gov/content/health/managing-your-health/child-behaviour-development/special-needs/autism-spectrum-disorder/build-your-support-team/hire-manage-service-providers>.

<sup>13</sup> *B.C. Family survey*, organized by Inclusion BC, Family Support Institute of BC, BCEd Access and B.C. Parents of Complex Kids, <https://bcdaccess.com/2020/04/30/report-on-covid-19-bc-family-survey/>.

supports. Further, despite needing the school-based supports, some families concluded that their children's physical and health needs were too great to risk their child returning to school. The November 2020 survey found that almost 38 per cent of families responding are still not receiving the same level of educational support as they were before the pandemic. *"I have not sent my son to school from September to November due to my fear of COVID-19,"* wrote one respondent. *"Supports are needed with social worker, health nurse, speech/language services, occupational therapy services."*

Support services that provide home visits were halted as well due to physical distancing directives and families' concerns with health risks. Services such as Aboriginal Infant Development Program and Aboriginal Supported Child Development (AIDP/ASCD) are not considered "essential services," and agencies delivering these services dealt with the pandemic in different ways. But Community Partners say all these services were wanting and needing guidance, yet initially had no support or recommendations from MCFD. Services ended up varying widely by organization, community and region.

For caregivers, the pandemic has left many trying to manage 24/7 support for their children. Maxed-out CYSN families have had to find even more hours in the day to meet their child's complex needs while at the same time home-schooling their other children, working from home or grappling with COVID-19-related job layoffs, and managing the complete collapse of their informal support networks. Fearing for their children's vulnerable physical and mental health, many families chose not to send their children back to school this fall.

## Mental health

The impact of the pandemic on the mental health of children, youth and their families is a critically important issue. In November, as part of our *Lessons in a Pandemic* series, our Office released a rapid research report entitled *COVID-19 and the Impact on Children's Mental Health* conducted by Simon Fraser University's Child Health Policy Centre. The evidence in that report clearly showed that we can anticipate dramatic increases in the number of children and youth experiencing mental health issues, including anxiety, depression and behaviour problems, as a result of the pandemic. The report showed that children who were struggling pre-COVID will experience more challenges, particularly those who are in foster care, who have pre-existing mental health conditions and who have disabilities.

RCY's November survey of families follows up a survey done at the start of the pandemic by our Community Partners, and reveals a significant worsening in families' perception of their mental health since the start of the pandemic. Almost 60 per cent of respondents in the November survey identified a need for mental health supports, compared to 32 per cent in April.

One family wrote of being so desperate for care for their teenage son with Down Syndrome after services collapsed in the first months of the pandemic that they had to recruit the boy's younger teenage sister to care for him so the parents could continue at their jobs. *"I ended up paying her with respite funding to acknowledge her support of our son with a disability,"* wrote the parent. *"On re-emerging after the lockdown, she began having panic attacks and increased anxiety. I think that the load of caring for her brother during the pandemic was a factor in mental health issues."*

Noted another respondent: *"As 'functioning' adults, we are often overlooked because we are considered average parents raising a child with special needs. We are not high-risk, but we are still drowning in lots of ways."*

## Introduction

Respite was a serious issue for many CYSN families before COVID-19. But what little was in place has disappeared almost entirely during the pandemic, even for families with the funding to pay for it. Respite providers have been reluctant to come into people's homes, while many families have been equally reluctant to risk their child's fragile health – or that of other family members – by bringing in outsiders.

*“When COVID happened, it hit my son the very first day – the day after spring break, when he wasn't able to go back to school,”* said a mother whose 15-year-old son's autism and attention deficit disorder significantly affect his ability to handle changes in his life.

*“His whole world just ended. So of course, behaviour challenges came out. His entire routine and life had been turned upside down. There were no summer camps, no day camps, limited activities. At the same time, our respite worker was no longer able to take him. All of that was going on for us, and meanwhile there was no information anywhere to help our family find another respite worker, or other supports.”*

For others, the abrupt changes caused by the pandemic opened their own eyes to just how overwhelmed their lives were, and in some cases plunged them into such profound crisis that their needs could no longer be ignored.

A mother of two-year-old twins with complex support needs due to their disabilities said the pandemic revealed to her “just how impossible my life had been.” She found herself no longer spending every single day driving her boys to medical and therapy appointments. She worries now, however, about the impact on the boys' future of all those missed appointments.

One parent contending with myriad family complexities said the pandemic ironically brought her family more support by sending her 10-year-old son into such crisis that he ended up committed under the *Mental Health Act* and finally getting the support he needed.

*“During COVID, my son's behaviour escalated so much that I got noticed,”* says the mother. *“He was an unmedicated, untreated child with mental health issues, with his routines kiboshed. Just at the brink of collapse, things kicked in. But it takes going through the system at the highest level of crisis to get the support you need.”*

Some Community Partners felt briefly hopeful at the start of the pandemic after an initial increase in communication with MCFD leadership and the government. They note that had the ministry continued with that approach, organizations and advocacy networks would have been able to clarify and address misinformation and act as vital conduits for the families they walk beside. MCFD's decision to maintain contract funding unaltered also allowed community organizations to continue working with CYSN families through the uncertainty of COVID-19, although meeting contract deliverables was a major concern.

With time, however, Community Partners experienced a near-total breakdown in communications and support from the ministry, with their recommendations ignored and a consultation process that felt like “lip service.”

## Family story – Bobbi and Fraser

Once upon a time, Bobbi had a career in the ski industry and very little exposure to the world she navigates today.<sup>14</sup> If anyone had asked her back then about how much help families of children with complex disabilities received in B.C., she would have guessed that they got all the help they needed.

Oh, what a difference six years can make. Bobbi is now a single mom in a small community raising her sweet and social boy, Fraser. He was born with a rare and complex developmental condition that has resulted in him being fully dependent, non-verbal and using a wheelchair. She and her long-time partner split up a year after Fraser was born.

Realizing the limits of supports available to a family like hers was “*a big wow moment*,” says Bobbi. “*It’s so obvious now that I’m in it, but it’s not obvious when you’re outside it. I think that’s a big problem in terms of advocacy and services for our families. Our families collectively have to make such an intense effort to be seen and heard for British Columbians to know even a little about what life is like for us.*”

Bobbi counts herself luckier than some families with complex children. She had enough money to buy an accessible van last year to transport Fraser. Many families go without, and pay the price in chronic back issues and limited inclusion in community for themselves and their child. Bobbi also found an accessible rental home – and after six months of waiting, a rent supplement to help cover the cost.

She owns a house in a remote B.C. village, where she and her son lived for a year after her separation until it became obvious they’d need to be closer to supports. She now rents the house out, which provides a small amount of monthly income.

While the pandemic has been difficult in many ways, one upside is that Bobbi’s 2019 earnings were sufficient to qualify her for the Canada Emergency Response Benefit (CERB). She’s finally able to meet more of her basic financial needs. When time allows, she continues to work at a recently launched home-based business in hopes of creating a little financial stability in the future.

The pandemic has compounded challenges for families. Like many other families with medically complex kids, Bobbi has to prioritize Fraser’s health, as a respiratory virus could be devastating for him. This means isolating from the supports that both she and her son rely on, including school, therapy and respite.

Fraser’s funding for basic medical supports comes through B.C.’s At Home Program (AHP), created in 1989 as part of the closing of the province’s large institutions where children with severe disabilities like Fraser used to have to live. The goal back then was to move funding that once went to the institutions into services that would support families to look after their children at home.

“*It was a robust program when it began*,” says Bobbi, who belongs to the B.C. Parents of Complex Kids network of families receiving AHP supports. “*But it’s been frozen in time ever since. The funding limits for medical equipment purchases haven’t changed in 30 years.*”

AHP respite amounts have increased just 10 per cent in three decades. The sole increase, implemented in 2019, increased monthly funding from \$233 to \$256 – about one extra hour a month of respite support. “*AHP has nothing to do with families’ actual needs*,” notes Bobbi.

<sup>14</sup> Names have been changed.

AHP has so many “holes in funding” for equipment purchases that much of what Fraser needs isn’t covered, adds Bobbi. He needs a device called a standing frame, which puts him in a weight-bearing position essential for his hip development. Unfortunately, funding gaps in the AHP left Bobbi having to apply to charity for this device, as well as another special comfort seat to give Fraser a break from his wheelchair while maintaining proper positioning.

*“Each of those cost approximately \$5,000. I have submitted applications to two charities recently and am happy to learn that the standing frame will be covered by the CKNW Kid’s Fund. The other application is on hold, because Variety the Children’s Charity has been so overwhelmed with recent requests that they have put a hold on most of their granting.”*

That families have to go to charities in the first place is “not OK,” notes Bobbi. *“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.”*

Bobbi and many other AHP families envy the very different funding style available to B.C. families whose children are diagnosed with autism. That funding allows families to direct spending much more flexibly and independently.

Bobbi sees the autism program as focused more on inclusion and quality of life, while the AHP “is failing to even meet the basic medical necessities of our children at this point.”

*“I find it really discriminatory that kids on the AHP are not given the same value as children on the autism program.”*

What would be her wish for a better future for her family?

*“That I could spend less energy trying to navigate all these systems, and that I had less financial uncertainty in my life – whether my charity application will be accepted, whether I’ll lose CERB, whether I’ll have the dollars for a caregiver,”* says Bobbi.

*“How about a guaranteed income that would allow us to strive and find other paid work as we can? An overhaul for AHP to bring it up to 2020? Having a child with disabilities in B.C. should not be a ticket to poverty and financial instability. Our kids deserve to be valued and have the right to be included equally in the social structure of B.C.”*

Basic financial support is “a foundational issue” for families of children and youth with special needs, says Bobbi.

*“It’s one problem that you CAN solve with money,”* she adds. *“The financial stress, knowing that we can’t make ends meet – that affects our kids’ development, as we are expected to fill in the funding gaps. Support inclusion. Support our kids’ development needs.”*

## History of CYSN services

Many of B.C.'s services for children and youth with special needs date back 30 years, to a period when B.C. was closing down large institutions where many children and adults with complex developmental, support and medical needs once had to live out their lives. At this time, some funding was shifted into the community to provide supports to families to keep their children at home.

That was the roots of the At Home Program (AHP), administered by MCFD. The program provides funding for respite, specialized equipment and medical benefits for children with eligible disabilities. Established in 1989 as a \$14.5 million annual program for 1,500 B.C. families, AHP funding caps for equipment needs and respite remain largely unchanged three decades on, despite the increasing complexity of disabilities and steady inflation that has left a 2020 dollar buying 56 per cent of what it bought in 1989.<sup>15</sup>

There are now 4,419 children receiving medical benefits through AHP, and 2,089 who qualify for respite.<sup>16</sup> Support from a medical professional for a family's application is not a guarantee of receiving services. Our Community Partners tell us that many are turned down.

Nursing Support Services are delivered by B.C. Children's Hospital through B.C.'s five health authorities to families of children and youth up to age 19 as well as schools and community agencies. Responsibility for the program originally resided with the Ministry of Health, but went to MCFD at the time of the ministry's creation in 1997, when the province was amalgamating all services to B.C. children and youth under the newly created ministry. It returned to the Ministry of Health several years ago.

To qualify for home nursing, children must be referred by a physician and have significant medical complexities in particular categories, or be palliative. Families and Community Partners report many issues with eligibility criteria as well as difficulties with poor provision of service by contracted agencies, sudden and unexpected withdrawal of services or loss of eligibility, and slow response on complaints. Many families fear "retaliation" if they complain, say our partners.

Other CYSN services are comparatively new to government, such as the Autism Funding Program, launched in 2001 in response to a class action lawsuit in which families of children diagnosed with autism argued that their children were entitled to therapy considered medically necessary.<sup>17</sup>

The program provides children diagnosed with autism under age six with up to \$22,000 a year for specialized therapies, parent training and equipment. School-age children receive up to \$6,000. But for families with children who are severely affected, a strong early intervention program can cost over \$40,000 a year. *"I'm disappointed that due to the pandemic, my daughter aged out in June for her larger funding and we barely got to use any of it,"* wrote one respondent in the November survey. *"She is now six, so that last bit of large funding is now gone and wasted."*<sup>18</sup> Families who are low-income – or who have recently immigrated and face barriers to services – struggle to access effective intervention; some make the difficult choice of putting their child in government care when severe behaviours overwhelm caregivers and put other children in the home at risk.

<sup>15</sup> Based on Statistics Canada Consumer Price Index.

<sup>16</sup> The 4,419 figure does not include children in care, who are eligible year-round for dental and optical services.

<sup>17</sup> MCFD funds B.C. autism services, while assessments are frequently provided by health authorities.

<sup>18</sup> MCFD did extend autism funding to children and youth who turned 6 or 19 years old during the period of March 15, 2020 to June 30, 2020, providing three additional months to use autism funding to purchase intervention services from the affected funding period.

## Family story – Anna and Zac

There's an impossible 12-hour drive and several thousand dollars in costs standing in the way of a young boy in a remote B.C. region getting a private assessment for autism.

And so his family waits for a publicly funded assessment closer to home. And waits – almost two years now, even though every health professional who has met four-year-old Zac advises his parents to get him assessed for autism.<sup>19</sup>

The length of time waiting has gotten to the point that Zac will soon have missed the entire first phase of autism supports in B.C. for children under age six. His family would have had up to \$22,000 a year through that program to buy therapies and supports for Zac if he'd had a diagnosis. But at age six, the bulk of funds for autism in B.C. shifts to school districts for educational support, and the amount going directly to families for therapies and supports is reduced to a maximum \$6,000 annually.

Zac's mother Anna was feeling hopeful in early spring, when the family was wrapping up a year of waiting that they'd been warned to expect. But then came word just as the COVID-19 pandemic took hold that Zac had been bumped down the list, and now faced another year.

*"I'm a strong advocate, but I'm worried,"* says Anna, who previously worked with adults with autism and recognized it in Zac when he was a toddler. *"My son is going to be five by the time he's assessed. At six, we get less funding, but that reduction is based on him having received the extra support before age six. Which he hasn't received."*

Zac has a number of other disabilities as well, and sees specialists for speech, hearing and vision problems. They all say he needs to be assessed for autism, says Anna. *"But we haven't been able to make it happen."*

The community child development centre did its best to support Zac in the first wave of the pandemic, when the centre closed.

Anna was *"quite impressed"* to land a weekly Zoom session with the centre's occupational therapist throughout the worst of the pandemic – more service than Zac got before COVID-19. Staff came by the family home with toys and equipment to ease Zac's chronic state of overstimulation.

But his speech therapy sessions dried up; there were just two online sessions in the four months when services were closed. Anna struggled to home-school her daughter, age seven, at the same time that she and her husband Alan found themselves busier than ever with their paid jobs. Alan's mother was a lifeline for the family for childcare, says Anna.

*"I was working extra hours at my job in the first months of the pandemic because people weren't coming in for their shifts,"* Anna recalls. *"Before COVID, we had a babysitter who took Zac one day a week, but that ended at the same time."*

The major disruption to daily routines was hard on Zac. He had been attending preschool at the child development centre, but the program was shut down. He no longer had access to the specialty rooms and large equipment at the centre that provides therapeutic play for children with special needs.

*"Zac has meltdowns so much, and that all got worse,"* says Anna. *"He's had problems sleeping, and can't tell us what's wrong. We've had to take him driving twice a day since this pandemic started, because his stress is just so blown up."*

Asked for her dreams for the future, Anna presents a small and practical list: Zac finally assessed; more resources in her community; more training to be able to continue working with her son to reach his potential.

*"If we could get that autism funding, things will be so much better,"* says Anna. *"But until then, I am so lucky to have an amazing mother-in-law."*

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<sup>19</sup> Names have been changed.



The Ministry of Education has a complicated formula for providing funding to school districts. For students designated with special needs, the funding is based largely on diagnosis. Community Partners note that because school districts can allocate this funding as they choose, there is no guarantee that children will receive the services they need. The amount that schools receive is insufficient for many of these children's needs, say our partners.

“Of the many surveys in the past few months, the supports listed have never been available to our family. My son's needs are just as great if not greater than those with autism, yet none of the services are available because he doesn't have the autism diagnosis.”

– from RCY November 2020 survey

AHP and other supports for community-based child development programs were born in a period when a global shift in thinking envisaged children with disabilities growing up with their families and included in their communities and schools, rather than institutionalized.

The lack of equity in how CYSN families are served in B.C. is a source of tremendous frustration for families and Community Partners. They note that many families of children and youth with special needs aren't able to access any supports. These include children and youth with complex behavioural needs such as attention deficit hyperactivity disorder and fetal alcohol spectrum disorder – children with presenting needs or diagnoses that do not meet CYSN eligibility criteria but whose behaviours can be extraordinarily challenging for families to manage in isolation.

This is emphasized in the Representative's upcoming special research report that shares stories of lived experience and reviews supports and services for children and youth with FASD. *“Because my child's diagnosis is FASD, we do not qualify for any support, yet my child needs one-to-one, 24/7 supervision as well as mental health support, occupational therapy, special therapy. We continue to be denied essential services,”* wrote a parent in our November survey.

Not surprisingly, the report finds that there are extremely limited supports for children and youth with FASD. We know of families whose children have been diagnosed with FASD who have attempted to access MCFD's CYSN Family Support Services but are deemed ineligible because the child has not been concurrently diagnosed with an intellectual disability – a key criterion to be eligible to access these supports.

This was true for all five families and their collective nine children diagnosed with FASD who engaged in the in-depth ethnographic research for this report, and emphasized by the quantitative data. Of the 925 B.C. children and youth diagnosed with FASD in the fiscal years 2016-19, approximately 75 per cent did not receive an intellectual disability diagnosis, making them ineligible for CYSN Family Support Services. Service provision based on diagnostic-driven eligibility criteria rather than functional need is highlighted as being one of the most critical and inequitable barriers that families and their children with FASD encounter in their attempts to access supports.

There is also concern that MCFD funding is not keeping up with the number of B.C. children with special needs. While total program funding for children with an autism diagnosis has expanded to attempt to keep up with the numbers of children being diagnosed, expansions in the At Home Program have been minimal.

*“How do you compare the mother who can't sleep because her child is in constant pain with the mother who can't sleep because she's worried her child might escape and make a break for the freeway?”* asks Deborah Pugh, Executive Director of ACT – Autism Community Training.

## History of CYSN services

*“You can’t. I think the real problem is that successive B.C. governments have starved other CYSN supports for years. That has split the special needs community into families of children with autism and families of children with other disabilities. I don’t think our society is so limited in our resources that we have to make choices between the two groups.”*

For the purposes of this report, we looked at the impact of the pandemic on families whose children are not in government care. That highlights another long-standing issue for CYSN families: the striking difference in support levels for children in care compared to those who remain in the family home.

The median annualized cost for a child or youth with special needs in MCFD residential care (either foster care or staffed residential care) was \$58,100 when RCY explored this issue in 2018. Residential costs to that point had been increasing by 12 per cent a year for the previous six years. The families of children who remain in the family home are not eligible for similar financial supports.

That’s not to say that foster homes receive sufficient support either, notes Community Partner and foster parent Rick FitzZaland, Executive Director of the Federation of Community Social Services of BC.

*“As a former foster parent of children with special needs for 20 years and a parent to two children with special needs, I am aware of the gap in supports for children in their families AND children in care,” he says. “Special needs children in foster families are also not getting enough support. Foster parents do not have a magic door to access services for the children in their care.”*

### What’s Needed?

“Meaningful respite. Family counselling. We never considered this ever until the past two months, but we are considering placing our child in care due to burnout and to salvage the rest of the family. School only offered one hr/day of all September, then two hrs/day starting mid-October. WE ARE BURNT OUT!!!”

– from RCY November 2020 survey



A mother and her son communicate using a PECS binder about what is happening next in their day.

Photo: Kristy Wolfe Photography

## Revelations from the pandemic

The direct relationships, expertise and knowledge of our Community Partners and CYSN families has been essential for this report.

Prior to RCY's involvement, Community Partners were engaging families across the province through surveys and reports aimed at gathering and sharing information on the impact of the pandemic. We have drawn from RCY's own work including the 2018 report *Alone and Afraid* and our November 2020 survey of 545 families, as well as the findings of the April 2020 B.C. Family Survey, the 2019-20 surveys and reports of families on the At Home Program and Nursing Support Services (B.C. Parents of Complex Kids), the October 2019 Select Standing Committee on Children and Youth report on children and youth with neuro-diverse special needs, First Call's June 2020 open letter to government, ACT's "Responses from Families" online feedback site, and archived media reports.<sup>20</sup> Together with our Community Partners, we have identified the following five issues as critical points for attention:

- ▶ **The pandemic amplified the inadequacies of a CYSN system outlined in *Alone and Afraid* and worsened the gaps, shortfalls and failures of an already fraught system.**

Quick action to address long-standing problems in supports for B.C. families of children and youth with special needs has never been more urgent in light of the inadequacies amplified by the pandemic. Families feel abandoned. Essential services fell apart and continue to be erratic. Respite broke down and processes based on diagnosis and assessment-based processes that were already extremely overloaded ground to a halt. Many families, especially those with medically compromised members, continue to struggle on without a minimal support system.

- ▶ **Equitable support for children and youth with special needs and their families does not meet international standards reflected in the *United Nations Conventions on the Rights of the Child* and *the Rights of Persons with Disabilities*.**

B.C. prides itself as an inclusive and equitable province. Canada is a signatory to international agreements confirming the rights of the child, which includes recognition of every child's inherent right to supports that "advance the child's survival and development to the maximum extent possible."<sup>21</sup> But the crisis that CYSN families were plunged into during COVID-19 highlighted and intensified deep and long-standing inequities.

- ▶ **A transparent and consistent communications plan is critically important to ensure families receive the supports and additional benefits made available to help them through extraordinary times.**

The provincial government implemented a number of relief programs and increased funding flexibility for CYSN families, announced April 7. This was an important recognition of the extraordinary impact of

<sup>20</sup> Articles in Vancouver Sun 1987-89. Kim Bolan, "Extra \$20 million pleases the disabled," *Vancouver Sun*, March 20, 1987, B8.

See also Alicia Priest, "Who will care for our Eddy?" *Vancouver Sun*, April 25, 1988, F5.

See also Ben Parfitt, "Let me care for son, mom pleads," *Vancouver Sun*, Dec. 17, 1988, G6.

See also Daphne Bramham, "Parents seek help to keep handicapped children home," *Vancouver Sun*, May 9, 1989, B1.

See also Gillian Shaw, "Handicapped aid plan lauded," *Vancouver Sun*, June 21, 1989.

<sup>21</sup> Article 6, *United Nations Convention on the Rights of the Child*.

## Revelations from the pandemic

the pandemic on CYSN families. But our Community Partners and families tell us that vital information often was not conveyed clearly, promptly or consistently through their own staff and community contacts. MCFD interim measures came into effect before its front-line workers knew what those measures were. As a result, CYSN workers liaising with families and the community organizations that serve them frequently did not know about the relief programs, who qualified, or how to apply.

- ▶ **Supporting CYSN families through a pandemic requires flexible strategies that fit these families' unique and diverse situations.**

Common pandemic worries such as job loss, health concerns, reductions in community services, the closure of child-care centres and the suspension of in-class learning assume much more significance for families of children and youth with special needs. More than a quarter of the families responding to the November survey reported a loss of employment income due to the pandemic, and 28 per cent reported a decrease in self-employment income. Sixty-five per cent experienced an increase in expenses due to the suspension of in-class learning. Yet the needs of CYSN families went largely unrecognized, and they were left to manage without essential services and no special consideration within their communities.

- ▶ **Our ongoing failure to provide adequate and consistent needs-based support for CYSN families is causing long-term harm that impacts every British Columbian.**

Insufficient support for CYSN families impacts community wellness. It hampers economic productivity and increases health costs over the long term. It also denies British Columbians the opportunity to be active and engaged citizens in their communities.

*“Please, government, think long term!” urges one mom with twin boys with cerebral palsy who need mobility, feeding and personal care support. “If you don’t fund a stander for my kids at the age when it’s recommended, you’ll pay hundreds of thousands of dollars later in surgical costs for them, and the pain they’ll have to live with will be so much more.”*

## Family story – Maria, Jon and twins Adam and Jason

Maria slept four hours last night.<sup>22</sup> And the night before that as well, and likely every night to come for the foreseeable future.

It's all she can ever manage as the main caregiver for two-year-old twin sons with severe disabilities. It's rough, but still a big improvement over the completely sleepless nights she and her husband Jon endured for months after the boys came home from hospital.

*“They came home at five months old. For six straight months after that, my husband and I had to alternate staying up all night with them, because they vomited five or six times a night and would die without someone there to make sure they didn't choke,”* Maria recalls. *“We had several doctors and other health professionals all trying to get us nursing services in that period, but we couldn't even get an assessment. That's still the case.”*

Twins Adam and Jason were born at 27 weeks and suffered severe brain bleeds at birth. The impact of those bleeds and other complications due to being born three months premature may leave them fully dependent on round-the-clock care for their lifetimes.

Jason's level of disability is more severe than his brother's – Jason can't move, while Adam can sit up but can't walk. Both boys have cerebral palsy, but Jason is more affected and requires tube feeding.

Those differences in a system that draws hard lines around eligibility have made for unusual funding decisions – like qualifying both boys for respite funding but only providing it to one. Adam is still waiting for his approvals, and has been for two years.

How that scenario plays out in real life is as no respite at all, says Maria.

*“We haven't had anyone in our home since the pandemic, but I want to find someone,”* she says. *“But to find a respite provider person for twins is going to be at least \$25 hour. That doesn't go far when only one of the boys gets the \$256 a month in funding.”* (It works out to 10 hours a month.)

The pandemic brought *“a long stretch of nothing”* in terms of services for the twins. One twin missed an important six-month vision test, and the other missed a hearing test. But the upside of suspended services was Maria's dawning realization of just how harried life had been for her and the boys with the pressure of medical appointments virtually every day.

*“I hadn't realized how impossible that life was to maintain until I could no longer do it. It's been nice to just be at home more,”* she says. *“The boys have actually started napping, which they never could do before. They seem happier now, and I get to spend a little more time working.”*

Like every parent of a child with severe disabilities, Maria's work has to fit into the gaps between the boys' care needs. She returned to her home-based work in November only to have one of the boys become critically ill for three weeks. *“I lost all my clients,”* she recalls.

She started up again in February, and COVID-19 hit. *“My husband has been an essential worker during the pandemic and that has been a real relief because otherwise we couldn't have covered our bills,”* notes Maria.

<sup>22</sup> Names have been changed.

Their combined incomes at least help them afford some of the high-cost therapies that public funding doesn't cover, she says. Equipment to help the boys stand isn't covered, and the maximum funding for leg braces that have to be replaced every six to eight months falls \$800 short every time.

However, a level of household income above \$65,000 also disqualifies the family for help from charitable organizations such as Variety the Children's Charity. *"Try living in the city with two special-needs children on \$65,000,"* Maria says.

What bothers her more than having to top up inadequate government supports is the feeling that her boys are being short-changed, with no apparent thought to the benefits of investing in children with disabilities.

*"Please, government, think long term!"* she urges. *"If you don't fund a stander for my child when it's recommended, you'll pay hundreds of thousands of dollars later in surgical costs, and the pain for him will be so much more."*

The family spends at least \$25,000 a year for additional physio and occupational therapy sessions with private providers, and refinanced their house in 2019 to free up \$40,000 for extra treatments for the twins. *"But it's worth every penny of debt,"* says Maria. *"It does make a difference."*

Maria knows families like hers are in a long, long line of people wanting more help from government. She worries what the school years will be like for her boys if things are this grim already and they're only two.

*"As a parent, you feel mostly alone. Does anyone care what happens to my kids? Anyone? Not really,"* she says. *"Obviously, you can't make this perfect for everyone. But seriously, just throw some money at this. At the very least, cover the full cost of essential equipment."*

# 1. The pandemic amplified the inadequacies of a CYSN system outlined in *Alone and Afraid* and worsened the gaps, shortfalls and failures of an already fraught system.

Maria and her husband are deeply grateful for the round-the-clock care their twin boys received during five months in intensive care.<sup>23</sup> Born with highly complex needs due to a syndrome caused by the placenta not connecting evenly to both fetuses, the boys required numerous medical interventions in those frightening months.

But it only took a few hours after bringing her fragile boys home from B.C. Children's Hospital for Maria to realize that her family was now mostly on their own.

*"For six straight months, my husband and I had to alternate staying up all night with them, because they vomited five or six times a night and would die without someone there to make sure they didn't choke,"* Maria recalls. *"We had several doctors and other health professionals all trying to get us nursing services in that period, but we couldn't even get an assessment. That's still the case."*

The family's plight speaks to the chronic lack of support that already existed prior to COVID-19 for many B.C. families whose children have special needs. The pandemic significantly worsened those problems, but CYSN families were suffering long before COVID-19.

Stringent eligibility requirements effectively screen out families whose children's needs don't fit into the box that has to be ticked for a certain service; in Maria's case, for instance, she has been told that both twins qualify for \$256/month in respite funding (which covers just four hours a week at minimum wage), but only one is receiving the funding while the other continues to wait for final approvals.

Try to buy respite services at minimum wage for two-year-old twins with significant developmental challenges and complex support needs, notes Maria. The family couldn't do it before the pandemic, and didn't try once COVID-19 hit and their household went into lockdown to protect the boys' health.

Current statistics on the number of children and youth in Canada with special needs are scarce. The 2006 Statistics Canada report *Disability in Canada* established a disability rate at that time of 1.7 per cent for children ages birth to 4, and 4.6 per cent for children ages 5 to 19.<sup>24</sup> Based on those rates, there were 37,319 B.C. children and youth with disabilities as of the 2016 census. In terms of special needs designation, the Ministry of Education says 77,232 B.C. students – 11.65 per cent of the K to 12 student population – received that designation in the 2019-20 school year.<sup>25</sup> The lack of current statistics underlines the importance of the first recommendation in *Alone and Afraid* – 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.

<sup>23</sup> Names have been changed.

<sup>24</sup> *Disability in Canada*, Statistics Canada, 2006.

<sup>25</sup> Education Ministry statistics, BC Teachers Federation newsletter, March 2019.

## Revelations from the pandemic

The majority of these children and youth do not receive funding or support from any CYSN program.<sup>26</sup> Eligible families may access specialized therapies and other child development services provided by community organizations under contract with government, but waiting lists are long and availability varies by community.

B.C. has a number of publicly funded services that support children and youth with disabilities, from the intensive care and specialized development services at B.C. Children's Hospital and Sunny Hill Health Centre to a diverse array of community-based therapies and family supports. But the level of support provided in a hospital setting is not replicated in the community for families, and access to even basic supports have been much more difficult in the pandemic.

B.C.'s main program for children with complex support needs arising from their disabilities – the At Home Program (AHP), created 30 years ago when B.C. was closing its large institutions – has been repeatedly cited by community organizations, this office, the B.C. Select Standing Committee on Children and Youth, and families as inadequate, inequitable and desperately in need of major reform.<sup>27</sup>

Our Community Partners note that AHP caps on funding for equipment, for instance, haven't increased since first established in 1989. The maximum available for respite care remained at \$2,800 a year for 30 years (in 2019 it was increased to \$3,080) even while today's dollar buys 56 per cent of what it bought in 1989.

That reality has left families facing the choice of either coming up with their own money to support their child's basic health and social needs, or see their children go without. A 2019/20 financial survey responded to by 75 B.C. families on AHP found that almost 60 per cent of families now spend at least \$5,000 a year of their own money to buy additional services, therapies and equipment for their children, and 36 per cent spend between \$8,000 and \$20,000 annually.<sup>28</sup> *"Our expenses for our child with Autism Spectrum Disorder are at least \$25,000 year,"* wrote a respondent in the November survey whose family qualifies for maximum \$6,000 in government support.

Higher-income families top up the shortfall to ensure their children receive the support they need. Lower-income families do without. Families who are unable to get the supports their children need feel they have no choice but to put their children into care. *"We have been told that in order to get the care and services that our child requires, we would need to sign a special needs care agreement and give up custody of our child, as the funding can then come from a separate budget,"* wrote a parent in the November survey. *"The need for us to do this to get required care and supports is a clear human rights infringement, and one that is regularly occurring with multiple families."*

Problems for the single mother living in poverty whose son Charlie was at the centre of RCY's 2018 report *Alone and Afraid* were intensified by Charlie not being diagnosed with autism until after his sixth birthday, despite showing signs of significant developmental delays before he was three.

<sup>26</sup> MCFD figures from December 2019 note 22,206 open CYSN Family Service Cases.

<sup>27</sup> Select Standing Committee on Children and Youth, *Children and Youth with Neuro-Diverse Special Needs*, (Victoria: Legislative Assembly of British Columbia), 2019, pp. 2-3.

<sup>28</sup> B.C. Parents of Complex Kids, "Financial Survey for Families of Complex Kids," 2019/20, <https://www.surveymonkey.com/results/SM-P8QW2FQG7/>.



*“That delay in assessment and diagnosis resulted in his family losing eligibility for \$22,000 in annual under-six autism funding and the early intervention services that money could have purchased – services that could have made a difference in his long-term development,”* noted the report.

The pandemic worsened wait times across the spectrum of CYSN programs due to the cancellation of all diagnostic services. Those shut-downs in turn shut families out of essential services that are only available to them once their child has a diagnosis, say Community Partners, and prevented those families from qualifying for pandemic-related benefits intended for them.

*“The minimal support we were getting before the pandemic was just barely able to help,”* said one mother. *“Well, COVID took it to zero.”*

Before the pandemic struck, our Community Partners reported feeling positive about moving forward collaboratively with MCFD on much-needed changes to what will eventually be a reworked CYSN Service Framework, even though details remain sparse and no new funding has been committed. However, communication processes fell apart as government attention shifted toward an emerging crisis affecting all of society, even while a decades-old crisis affecting a small and hidden community deepened.

*“Long-standing relationship problems and a lack of trust was further strained by the pandemic, to the point that families feel completely betrayed,”* one Community Partner told RCY during consultations this summer. *“Trust must be restored.”*

## 2. Equitable support for children and youth with special needs and their families does not meet international standards reflected in the *United Nations Conventions on the Rights of the Child* and *the Rights of Persons with Disabilities*.

When Lucia returned to B.C. four years ago, she presumed her son Eduardo would get the support he so urgently needed.<sup>29</sup> He had been born healthy a year earlier outside of Canada, but the mild jaundice that briefly affects many newborns had emerged in a rare toxic form a few days after his birth and left him with cerebral palsy, chronic pain, breathing difficulties and without sight or hearing.

Eduardo, now 5, did get connected to vital medical services at BC Children's Hospital soon after the family of four arrived in Greater Vancouver. But his family's inability to get any help beyond \$256 a month for a few hours a week of respite highlights a crisis of inequity that not only pits the needs of children with special needs against children without them, but pits the families of children with disabilities against each other in a competition for chronically scarce supports.

Eduardo requires 24-hour care. His needs are immense, but not so severe as to require a tracheostomy to help him breathe, says Lucia. That has left him unable to qualify for B.C.'s Nursing Support Services program, which provides funds for eligible families to hire in-home nursing care.<sup>30</sup>

### **Calls to Action to improve the health and well-being of First Nations, Métis and Inuit children and families**

- **Truth and Reconciliation Commission – Principle #5** – Reconciliation must create a more equitable and inclusive society by closing the gaps in social, health and economic outcomes that exist between Aboriginal and non-Aboriginal Canadians.
- **United Nations Declaration on the Rights of Indigenous Peoples – Article 22** – Particular attention shall be paid to the rights and special needs of indigenous elders, women, youth and children and persons with disabilities in the implementation of this Declaration.

<sup>29</sup> Names have been changed.

<sup>30</sup> This program is administered by B.C. health authorities under the jurisdiction of the Ministry of Health.

## Family story – Lucia, Alexander and Eduardo

Four years have passed since Lucia returned as a newcomer to Canada, the country of her birth.<sup>31</sup> It was a wrenching decision to leave family behind in another country, but she and her husband knew that their youngest son urgently needed the kind of medical and social supports that Canada is known for.

Lucia and her children are Canadian citizens, and husband Alexander is a permanent resident. The family made the tough choice to return to Canada when their son Eduardo was a year old.

Eduardo had suffered a massive brain injury from liver problems soon after birth. Unlike the mild jaundice that briefly affects many newborns, Eduardo's jaundice emerged in a much more toxic form known as kernicterus. It left him with severe cerebral palsy, breathing difficulties, chronic pain from dystonia and unable to see or hear.

Eduardo's level of disability is so severe that the family was attached to a multitude of services at BC Children's Hospital within six months of moving to B.C. with their two boys, ages three and one at the time. Lucia felt hopeful that the family was going to get the support they needed.

And in terms of Eduardo's medical treatments, he has. But social supports for the family have been largely non-existent, even though Eduardo's profound level of disability is evident to all.

The nights are particularly long for Lucia and Alexander. Eduardo's intense discomfort and reflux means that one or the other of them regularly spend nights with him in the rocking chair, trying to keep his crying to a minimum.

He doesn't have the "right" disabilities to qualify for Nursing Support Services, says his mom. A primary eligibility criteria for respiratory conditions is that children have a tracheostomy – a tube in the windpipe to help them breathe. Eduardo doesn't require one.

The family qualifies for \$256 a month for respite through MCFD's At Home Program. Lucia says finding trustworthy respite for a complex child such as Eduardo is virtually impossible on what works out to about four hours a week at minimum wage.

So she and Alexander just try to get by. So profoundly impacted by his disability that he can't even hold up his head, Eduardo, now 5-years-old, is effectively a 20-kilo newborn, says Lucia – one who lives with his exhausted parents and big brother in a second-floor suite with no elevator or wheelchair accessibility.

*"My husband doesn't work. We tried for a while but couldn't do it," says Lucia. "He was doing a night shift so he could help in the day, and it was so hard. But I have a job I can do from home that's very flexible, so I can work for a bit, help with Eduardo, work more, and keep doing that until 8 p.m. every day. This is the only thing that works for us right now."*

The pandemic barely registered on the overwhelmed family, as they'd been self-quarantining since January while getting ready for major surgery that Eduardo had in February.

<sup>31</sup> Names have been changed.

When COVID-19 restrictions came down in mid-March, the family had yet to emerge from the surgery quarantine. Lucia and Alexander were already homeschooling their oldest son to ensure he didn't bring home any germs that would affect Eduardo's fragile health.

The double quarantines have left Eduardo without any therapies or in-person medical appointments since early January. His parents worry about the lack of therapies, but at the same time are relieved to have a break from driving Eduardo to his many appointments. Any car trip requires multiple stops to adjust Eduardo in his car seat and ease his pain on a bad day.

Lucia worries about the impact of the prolonged social isolation of back-to-back quarantines on her older son, age 7. *"He hasn't been able to go to school or see his friends for more than six months. We're concerned about the level of psychological stress this brings to him,"* says Lucia.

Like many parents of children and youth with special needs, Lucia wishes the government paid families to care for their complex children, given that it's *"more than a full-time job."*

Eduardo needs 24-hour care and supervision. If he was in government care, a foster family would be paid as much as \$3,000 a month to care for him.<sup>32</sup> That support would make such a difference for her family, says Lucia.

*"Caring for a child who is going to be fully dependent for their whole life should be recognized as a job, because otherwise the government has to take care of our children,"* says Lucia. *"I can't say I haven't thought about that. But I really don't want that to happen to our family."*

An income for family caregivers would not only let families concentrate fully on caring for their child, but free up more time for the endless paperwork and requests to charities to help families buy essential equipment, she adds.

*"Our income is under \$40,000, so we have to be applying to all the charities out there,"* Lucia says. *"Having to do that adds to the big delays for everything. From the moment the therapist tells you that you need a certain piece of equipment, it could be eight months or more before you get it. And then there's all the fittings, and me bringing Eduardo again and again to appointments, with no accessible van or the money to buy one."*

Lucia has a degree in International Development Studies, and worked in that field before moving to Canada. Alexander is a sociologist and occasionally works as a tutor.

But finding work in a profession of your choosing isn't an option for many parents of severely disabled children. Instead, they look for the kind of work that will fit into small gaps amid the round-the-clock needs of their child – work that allows them to suddenly take off a day, a week, or even longer if their fragile child gets sick or needs surgery.

*"We can't work. We can't contribute to a pension plan. We can't get a mortgage. We can't save any money,"* Lucia says of her family's situation. *"We are unpaid caregivers, and therefore our ability to work is severely limited. We represent an extremely vulnerable population. No one recognizes our level of distress and suffering."*

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<sup>32</sup> Basic monthly rate plus supplement for children 11 and under rated Level 3, B.C. Foster Care.

In B.C., the multiple funding streams and approaches for children and youth with special needs provide differing levels of support based solely on the type of disability a child has and whether that child has an eligible diagnosis. Our Community Partners point out that a child who qualifies for support and one who doesn't may both require equal levels of support to function in daily life, but individual level of need isn't factored into funding decisions.

The emphasis on diagnosis-based rather than needs-based eligibility creates significant inequality among CYSN families, and results in hardship for families whose children's needs don't fit within a program's narrow criteria. Our partners say that the structuring of B.C.'s CYSN programs often leave families feeling like the goal is to provide the absolute minimum support possible, rather than help children realize their potential.

These inequities have become all the more evident during the pandemic. The suspension of in-class learning left children and youth with special needs without vital school-based services – services that may be the only support a child receives if they don't qualify for the CYSN program. *“Without my child attending a brick-and-mortar school, we found that most distance learning doesn't offer speech therapy or occupational therapy, so we used all of his autism funding for services already and it's only November,”* wrote a respondent in last month's survey.

Access to school-based services is an ongoing concern for many families, who fear sending a child with complex health issues into an environment where COVID-19 transmission is a constant risk.

The divide has also deepened for families who lack the technology or internet connectedness to be able to access virtual services during COVID-19, say our Community Partners. Individual therapists' choices on whether to provide virtual services have added to the problem. Language and cultural barriers have complicated access for families as well.

With shortfalls growing every year in CYSN programs not indexed to inflation, families face either making those shortfalls up themselves or seeing their children go without. One family took out a \$40,000 second mortgage last year to cover therapies for their child. Essential equipment for children's development, health and comfort is only partially funded or not funded at all.

In Canada, while Jordan's Principle and the principles of substantive equality require that all First Nations children – on and off reserve – are provided with publicly funded benefits, supports, programs, goods and services that meet their particular needs and circumstances on a substantively equal basis with non-First Nations children, there are still large inequities.<sup>33</sup> The First Nations Caring Society recently won its seventh non-compliance hearing at the Canadian Human Rights Tribunal against the federal government. There continues to be ongoing funding inequities and jurisdictional conflicts that impact First Nations, Métis and Inuit peoples, profoundly impacting those with special needs.

Families with lower incomes and limited or no assets don't have the opportunity to go into debt to help their children. It hurts parents to see children from wealthier families able to buy the kinds of therapies and supports that those relying on the public system simply can't access. Our Community Partners note that *“even well-off families are on the edge”* now. Overwhelmed families have found themselves contemplating putting their children into government care just so the child will receive more access to vital supports that are currently unavailable to them.

<sup>33</sup> *“Jordan's Principle,”* Government of Canada, last modified Oct. 5, 2020, <https://www.sac-isc.gc.ca/eng/1568396042341/1568396159824>.

## Revelations from the pandemic

*“As I watch those who have gone with private physio make leaps and bounds in their development, it saddens me that we haven’t been able to provide that for our son,”* says one mom.

Disparities are also growing among families who do receive services. Children with major needs can still end up screened out of supports, as exemplified by this excerpt from *Alone and Afraid* examining the disturbing lack of support for a young First Nations boy and his mother.

*In her At Home Program assessment, the Nursing Support Services nurse recommended Charlie be approved for both medical and respite benefits. The eligibility committee subsequently determined that Charlie was not eligible for both benefits because he was only rated as fully dependent in two categories of daily living and “close to” fully dependent in the remaining two categories. The committee informed his mother by letter that she would have to choose one or the other, adding that there was a wait list for respite.<sup>34</sup>*

As previously noted, funding for children diagnosed with autism was mandated by a court decision, but while MCFD’s autism model is the envy of CYSN families who have to rely on the ministry’s chronically underfunded At Home Program, there is significant inequity within the Autism Funding Program as well – beginning with diagnosis.

Higher-income families may be able to afford to pay for a \$5,000 private assessment for their child which allows for immediate access for autism funding. Lower-income families face an average wait time of anywhere from 45 weeks on Vancouver Island to 67 weeks in the North. Referrals for an autism assessment have increased 54 per cent since 2012/13. Average waits for those assessments have grown ever longer since 2015, a concern that RCY brought to the attention of the Ministry of Health in *Alone and Afraid*. *“The wait lists are incredibly long, and due to COVID the anxiety and behaviours of our child increased, affecting the whole family,”* noted a November survey respondent. *“These wait lists add to the anxiety felt by our family.”*

The economic impact of providing round-the-clock care to a child creates major inequities for families, particularly for single-parent families. Almost a fifth of the 75 families in the At Home Program who responded to the 2019/20 financial needs survey were single parents.<sup>35</sup>

Even in two-parent families, care requirements significantly complicate families’ ability to maintain paid work outside the home. Eighty-seven per cent of the families in the AHP survey said their children’s medical and therapy appointments interfered with their ability to maintain paid work. Twenty per cent of families reported a household income below \$35,000 before the birth of their complex child, but that jumped to 30 per cent once they became caregivers as well as bread-winners.

Lucia’s husband can’t work outside the home because of Eduardo’s extensive care needs, so the family scrapes by on whatever Lucia can earn through a small home-based business she works at while helping her husband with Eduardo.

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<sup>34</sup> *Alone and Afraid*, p. 14.

<sup>35</sup> Conducted by B.C. Parents of Complex Kids.

*“Caring for a child who is going to be fully dependent for their whole life should be recognized as a job, because otherwise the government has to take care of our children,”* says Lucia. *“I can’t say I haven’t thought about that. But I really don’t want that to happen to our family.”*

Her comment raises another inequity: the difference in government support depending on whether children are in the care of their family or are in government care – a point that our Community Partners also underline. Foster parents receive government funding for children in their care. Lucia questions why CYSN families trying to keep their children out of government care can’t be similarly supported.

*“We can’t work. We can’t contribute to a pension plan. We can’t get a mortgage. We can’t save any money,”* she points out. *“We are unpaid caregivers, and therefore our ability to work is severely limited. We represent an extremely vulnerable population. No one recognizes our level of distress and suffering.”*



Multiple specialists assess a young girl’s hip mobility during a day of appointments.

Photo: Kristy Wolfe Photography

### **3. A transparent and consistent communications plan is critically important for ensuring families receive the supports and additional benefits made available to help them through extraordinary times.**

A provincial decision to let CYSN families use respite funds more flexibly during the pandemic was a big relief for Vanessa.<sup>36</sup>

Her family struggles at the best of times to find respite for twin eight-year-old sons because of the boys' complex autism-related behavioural challenges and chronic pain. The situation went from difficult to downright impossible during COVID-19, when many respite providers were no longer willing to come into people's homes.

But Vanessa would have never known she had that flexibility had she not sat in on a conference call with MCFD after an advocacy organization flagged it to families. Vanessa had to chase down a recording of that call to play for her CYSN worker, who had no idea that respite rules had changed.

That was not an uncommon experience for CYSN families. Many of the 545 families who responded to our November survey noted that they were left to rely on social media and word of mouth to find out about emergency measures and how to access benefits. Our Community Partners say the absence of consistent and clear communications from MCFD has been a common complaint from CYSN families. The B.C. survey of 1,055 CYSN families in April highlighted the extent of the problem in the initial weeks: when families were asked "What do you need right now during the pandemic?" almost 58 per cent said their major need was just to know whether their family was eligible for any pandemic supports.<sup>37</sup> Eight months later, that number remains virtually unchanged, with 60.37 per cent of respondents in our November survey still identifying that as a major need.

Responses in our November survey reveal communication problems between CYSN families and their MCFD workers that were poor to begin with and have worsened in the eight months of the pandemic. Seventy per cent of respondents reported having either no contact or very little with their CYSN worker in the first three months of the pandemic. That percentage rose to 89 per cent by the end of October.

MCFD participated in one virtual town hall on April 3 in partnership with the Education and Health ministries, and after interim measures were introduced April 8, made that information available to families and family-serving agencies via the COVID-19 information portal on the B.C. government's home page. Letters detailing the measures were sent to key CYSN partners.

<sup>36</sup> Names have been changed.

<sup>37</sup> B.C. Family Survey organized by Inclusion BC, Family Support Institute of BC, BCEdAccess and B.C. Parents of Complex Kids.



In comparison, Community Living B.C. launched the first of its ongoing weekly bulletins and other updates to families and service providers on March 31, and as of Nov. 17 has hosted nine teleconferences for individuals and families receiving CLBC services, all of them recorded and available on its website. Families, clients and service providers could sign up for regular email updates. Along with developing detailed FAQs and links to other resources related to the pandemic, CLBC created separate plain-language guides to its COVID-19 emergency funding for service providers, people with direct-funding agreements, and home-share providers.

MCFD's response was marred by communication challenges that our Community Partners tell us started within the ministry itself and extended out to communications with families and community organizations. People scrambled to find information on emergency benefits. They searched in vain for MCFD help in finding alternative supports for their children.

Our partners told us that communications about pandemic benefits appear to have been largely left up to individual CYSN workers to decide how to handle. Families report that their social workers sometimes knew nothing about emergency benefits, and that the responses of those who did varied widely. *"I never heard from anyone at all,"* said a respondent in our November survey. *"I felt totally abandoned. I had to actively reach out over several months to get any follow-up."*

## Family story – Vanessa, Dunc and twins Christopher and Kevin

It's 8 p.m. on a Sunday night, and Vanessa has finally found a few minutes to talk about what life has been like for her family during the COVID-19 pandemic.<sup>38</sup> She has one of her eight-year-old twins with her in the car as she talks, because there isn't really a minute in any day ever when she isn't in caregiver mode.

The boys were diagnosed with autism when they were two-and-a-half. Facing a wait of 18 months or more for a publicly funded diagnosis, the family opted to pay several thousand dollars themselves for a private assessment to be able to access funding and therapy sooner. Vanessa is grateful to have gotten past that hurdle; when the pandemic hit, all assessments were halted, adding further delay for families.

Twins Christopher and Kevin have numerous challenges, from speech and learning issues to difficult behaviours. One twin regularly experiences excruciating pain, still undiagnosed. *"When Christopher isn't doing well, none of us are doing well,"* says Vanessa.

Access to tele-medical appointments since the start of the pandemic was a surprising upside to an otherwise miserable period for the family. It spared Vanessa having to drive the boys to their medical appointments – a difficult process at the best of times, and unbearable when Christopher is in pain.

Beyond that small bright spot, however, the pandemic was a grim time for the B.C. family. With routines disrupted and respite lost as services shut down and support people stayed home, Vanessa and husband Dunc were on their own. The twins qualify for 14 hours of respite, but three of the four people they count on for respite weren't available in the first months of the pandemic.

Dunc kept working at his paid job and in fact got even busier, as his work had relevance to the pandemic. But that just meant even longer hours for Vanessa alone at home with the twins.

*"Things got a lot worse because of COVID,"* says Vanessa. *"Christopher screams when he's in pain or stressed. That terrifies his brother, and I'm alone in the house with them. That's how it went until things started opening up again. My husband and I are both mentally strong, but if you just keep coping and holding it together, nobody pays you any attention."*

Everything has been harder during the pandemic, notes Vanessa.

Stores added early-morning shopping hours for people with disabilities, but that didn't include parents of children with disabilities. Dunc – immune-compromised himself – usually picked up groceries at around 7 p.m. on his commute home, but that fell apart when stores shortened opening hours.

And while Vanessa and Dunc were "essential workers" in terms of providing 24/7 services to their high-needs children, they didn't have the official designation that would have qualified them for the benefits offered to that group.

*"Getting food and prescriptions suddenly became one of our biggest challenges,"* says Vanessa. *"The whole COVID thing made me see that the community is completely unaware of us. Nobody knew what we were going through. It felt like kids with disabilities were a total after-thought."*

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<sup>38</sup> Names have been changed.

B.C. set aside special funds to help families like Vanessa's during the pandemic. But poor communications meant many families didn't know what they were eligible for or how to apply. Tapped-out families were daunted by a whole new pile of paperwork to complete. They also feared having to give up one hard-won benefit in order to get another.

Vanessa was told she wasn't eligible for the \$225/month emergency benefit, for instance.

*"For everything that happened, I jumped through so many hoops, filled out so much paperwork, only to be told I didn't qualify," says Vanessa. "It sure would have been nice to have skipped that."*

Autism Community Training (ACT) has been an important resource for Vanessa during the pandemic. It was on ACT's website that she learned about a conference call with MCFD and discovered that families were newly approved to use respite dollars more flexibly.

Vanessa and Dunc used some of the freed-up funds for a few takeout meals, saving themselves the usual 11 p.m. dinner prep after the boys' bedtime.

Meanwhile, the stuff of life has kept piling up, with no spare moment to deal with any of it. Two federal child benefits and prescription coverage have been temporarily lost because the family's taxes aren't up to date. An appointment at BC Children's Hospital to assess Christopher's nervous system disorder came available, but with 17 forms needing to be filled out within a week to make it happen, it didn't happen.

*"My dream? More support," says Vanessa. "Generally we get respite, but it's complicated because of two kids, and I'm home alone a lot with the two of them. As a result of COVID, I was with Christopher for 10 to 11 hours every day, then Dunc would get home around 7 and take him so I could have a 'break' with Kevin."*

*"Dunc works 11 hours at a computer in his paid job and then spends three or four hours with our high-needs son every night. It's a psychological and physiological recipe for disaster! Really, there's never a break for either of us. Services for families like ours may look great on paper, but that's as far as it goes."*

## Revelations from the pandemic

Some MCFD workers jumped in with enthusiasm: *“My social worker reached out to me about my respite contract and told me about using respite money for other services. I shared my family’s struggles around grocery shopping and she was able to access emergency funding for us,”* one family noted in the B.C. Family survey. A respondent in the November survey wrote that the family’s CYSN worker *“is amazing, but I get a sense the office is very overburdened.”*

Others seemed to disappear under the weight of their CYSN caseloads, which in 2018 averaged 131 families per CYSN worker.<sup>39</sup> *“I haven’t been contacted, which gives me a sad feeling,”* wrote a survey respondent. *“[The social worker] must be overwhelmed. I had no idea there were resources available.”* A respondent to our November survey wrote, *“Were we eligible? Our CYSN social worker has changed three times since 2016, so we don’t even know who it is right now.”*

*“My CYSN worker has done an exemplary job of maintaining her connection with my family throughout the pandemic. One of the biggest challenges I think SHE has faced is internal disorganization when new supports are being rolled out. I knew about the emergency relief measures before she did.”*

– from RCY November 2020 survey

CYSN workers are key points of communication for families, and especially important in a crisis situation like the pandemic, when every aspect of life is affected. But the April 2020 survey of more than 1,000 B.C. families in MCFD’s At Home Program found that only 30 per cent had connected with their CYSN worker. Another 27 per cent were still waiting to hear back after reaching out to their social workers, while five per cent were unsure they even had a social worker, or who that person was. As noted previously, RCY’s followup survey in November identifies worsening communication problems for families trying to connect with their CYSN worker. Forty-five per cent reported they had no contact with their worker during the six months of emergency measures. The burden the system places on CYSN workers is unmanageable, especially in a time of crisis.

Clearer communications were especially needed around the \$225/month emergency benefit that the B.C. government announced for CYSN families, prioritized initially for families whose children were in the queue for respite services but hadn’t yet received a service. Community Partners reported mass confusion as to who was eligible and how to apply, and families told us they were worried that applying for the temporary benefit might count against them when it came to other hard-won benefits and services they had cobbled together for their child. Those who did manage to secure the benefit discovered that there were no respite services available to be bought anyway; in-home services were largely unavailable in the first months of the pandemic.

Some 55 per cent of families participating in the B.C. Family Survey were eligible for the emergency benefit.<sup>40</sup> Yet a scant 6.8 per cent of them were receiving it at the time of the April 30 survey as the funding was not sufficient to meet the number of children whose families wanted the support. Only 50 families out of 1,055 surveyed were receiving it noted the Community Partners who put together the survey. *“The measures that are meant to support them are not working for these families.”*

Access to the \$225 benefit had improved by the November survey, but still just 28 per cent of respondents reported receiving it.

<sup>39</sup> *Alone and Afraid*, pp. 10-11.

<sup>40</sup> April 2020 report from Inclusion B.C., Family Support Institute of B.C., BCEdAccess and B.C. Parents of Complex Kids.

In gathering information for this report, the Representative sought figures from MCFD on how many B.C. families received the \$225 Emergency Relief Support Fund. To be eligible for this short-term benefit, MCFD guidelines prioritized families who had been deemed eligible for specific CYSN Family Support Services but who were not yet receiving them. Families already receiving a service could also receive the short-term benefit.

MCFD has told our Office that the ministry's goal was to reach 1,300 of the 2,672 eligible families in the first round of the benefits, April to June. The second round was July to September, during which time the ministry says the goal was to reach 2,600 families.

There was regional disparity across the province in how the fund was administered. The graph below shows the regional distribution of these benefits.

Service Delivery Area	Number of Children with requests for At Home or Direct Funded Respite <sup>41</sup>	Number of families who received the CYSN Emergency Relief Support Fund April 1 – June 30, 2020	Number of families who received the CYSN Emergency Relief Support Fund July 1 – Sept. 30, 2020
Kootenays	109	28	45
Okanagan	268	105	188
Thompson Cariboo Shuswap	170	88	177
East Fraser	196	124	212
North Fraser	474	147	280
South Fraser	636	223	470
Vancouver/Richmond	264	166	333
Coast/North Shore	20	56	87
South Van Island	219	123	231
North Van Island	103	119	254
Northwest	58	61	108
North Central	136	66	147
Northeast	19	30	49
<b>TOTAL</b>	<b>2,672</b>	<b>1,336</b>	<b>2,581</b>

<sup>41</sup> According to MCFD eligibility criteria, CYSN Emergency Relief Support Funding was for families who were already deemed eligible for CYSN Family Support Services, and who had been approved for specific services, but who were not yet receiving them. When asked for the total number of families eligible for CYSN short-term Emergency Relief Support funding, MCFD provided a regional breakdown of children with requests for At Home or Direct Funded Respite.

## Revelations from the pandemic

A failure to consult with families and service providers before finalizing the details of the pandemic-related benefits also led to major disconnects.

For example, families of children with autism diagnoses were temporarily approved to spend 35 per cent of their funding on equipment needs during the pandemic instead of the usual 20 per cent.<sup>42</sup> MCFD also briefly suspended the requirement that CYSN families secure the signature of a designated health professional on new equipment purchases.

That should have been good news for families, who found themselves needing more equipment at home when development centres closed in the first months of the pandemic. But communications were inconsistent and some of the families RCY spoke with didn't know that the policy had been temporarily suspended. Unprecedented closures of professional services in the first months of the pandemic left those families trying to get the attention of health professionals and CYSN workers now consumed by entirely different priorities.

A similar disconnect happened with the emergency benefit. Intended to provide equivalent monthly funds for families whose wait-listed children hadn't yet received a respite service, the measure presumed that respite would carry on as always during a pandemic. In reality, Community Partners point out that respite services have widely fallen apart in the pandemic due to providers' unwillingness to enter people's homes during COVID-19 and families' concern for their health-compromised children.



Nearly 60 per cent of families responding to the B.C. Family Survey reported not being able to access any MCFD pandemic benefits. Seventy per cent of those who had qualified for respite before the pandemic ended up unable to use their funding. As of our November survey, 55 per cent of families eligible for respite supports still haven't been able to use their funding. MCFD did implement more flexible use of respite funding in response to the pandemic and will keep that measure in place until March 31, 2021.

*“For everything that happened, I jumped through so many hoops, filled out so much paperwork, only to be told I didn't qualify,” says Vanessa. “It sure would have been nice to skip that.”*

A working mother breathes in a moment of silence at her home, while her children and husband go for a walk during the first phase of the COVID-19 pandemic.

*Photo: Krystle Schofield Photography*

<sup>42</sup> This temporary change ended Sept. 1, 2020.

## 4. Supporting CYSN families through a pandemic requires flexible strategies that fit these families' unique and diverse situations.

Emma was born full-term and healthy on her parents' farm in a remote part of B.C.<sup>43</sup> But around the time of her first birthday, she started to lose function.

She lost her ability to walk, and then sit. She stopped talking. Her frightened parents spent two years visiting specialists and trying to figure out what was happening. Now age six, Emma was eventually diagnosed with a rare genetic mutation that manifests similar to severe cerebral palsy.

Despite her profound level of disability, Emma is otherwise healthy. That ought to be a point of relief for her family. But in fact, it counts against them in terms of qualifying for B.C. supports intended for families like Emma's, such as Nursing Support Services, administered by B.C. health authorities.

The inflexible nature of services and supports for families of children and youth with special needs has been a major concern for families and our Community Partners for decades. With every child and family situation unique, our partners say that the tick-the-box forms and restrictive eligibility criteria of many CYSN programs deny families essential supports solely because their child's needs don't fit into the right boxes.

Some CYSN supports under MCFD are tied to a specific diagnosis, such as the Autism Program. Others, such as the At Home Program, are based on a child's level of function with no consideration to actual need. These highly specific eligibility requirements for CYSN services have long been major barriers for families needing support, as the actual needs of a child or their family are not factors in determining who receives support.

One mother told us of her young son's severe breathing problems and reflux that regularly leave his exhausted parents no option but to rock him all night long in their laps so that he can sleep. But his breathing difficulties aren't quite serious enough to require a breathing tube, so he doesn't qualify for home nursing services.

Another mother of two-year-old twins with cerebral palsy and significant mobility, feeding and personal support needs receives respite for only one of them; the other is "*not quite disabled enough*" to have made it past the wait-list he has been on since birth.

When CYSN funds can't be put to use by families due to pandemic restrictions, families should be able to roll over those unused funds or access them for other essential needs, say Community Partners. "*Families will need those funds to support their child to compensate for services lost,*" says Erika Cedillo, Director of Public Policy and Programs with Inclusion B.C. "*They may want to increase frequency of supports when restrictions are lifted.*"

<sup>43</sup> Names have been changed.

## Family story – Jacquie, Frank and Emma

A global pandemic plays out a little differently 10 kilometres down a remote B.C. logging road, where Jacquie and Frank farm their land and live off-grid with their three children.<sup>44</sup>

The two oldest children have always been home-schooled, so no change there. The respite and supports they desperately need for their youngest child have been incredibly hard to come by since long before COVID-19, and there certainly was no change on that front either.

*“People will sometimes say to me that having a child with severe physical disability must be like having a newborn. Well, yes, except a newborn passes through that stage. My child never will, and she grows and gets heavier,”* says Jacquie.

Six-year-old Emma was born with a rare genetic mutation. 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.

*“Emma was born on our farm, healthy and normal,”* recalls Jacquie. *“But at one, she started to lose her skills. First it was her ability to stand, then to sit. We went through a couple years of diagnosis processes as they tried to figure it out. It turned out to be a genetic mutation that my husband also has, but he’s not affected.”*

Emma requires round-the-clock care. COVID-19 didn’t change that, though it intensified the family’s long-standing challenge around finding someone to provide respite. Some of the therapies Emma usually gets at the community child development centre were provided in-home in the first months of the pandemic, *“but too infrequently to make a difference,”* says Jacquie.

Emma qualifies for the maximum \$256 a month in respite funding. But Jacquie says it’s been near-impossible to find a provider who is not only skilled at the intense care Emma needs, but willing to work only four hours a week at minimum wage and has a car for the 20-kilometre round trip from the nearest town.

The family has never qualified for the medical benefits or Nursing Support Services available to other B.C. families of children and youth with special needs. Emma’s condition doesn’t fit the narrow categorizations used to determine eligibility. She has severe disabilities, but is healthy.

So Jacquie and Frank mostly manage on their own. Frank does a lot of the daytime work while Jacquie home-schools the older children. Jacquie sleeps with Emma at night to be able to reposition her repeatedly when the girl’s muscles spasm painfully.

The couple are deeply committed to living off the land, but packed up their four children and moved to Vancouver for a couple of years after Emma was diagnosed, believing they would find more support in an urban area. Instead, they struggled mightily in Canada’s most expensive city, and never could access additional services anyway. They came home to southern B.C.

Like other families enrolled in the At Home Program (AHP) and receiving child development services, Jacquie sees the flexibility enjoyed by families in B.C.’s autism program and wishes that same flexibility was available for Emma.

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<sup>44</sup> Names have been changed.



But the funding rules are dramatically different depending on whether a child or youth qualifies for autism support through MCFD or for the older provincial programs like AHP, introduced for children with severe disabilities back when B.C. was closing down institutions in the late 1980s. Unless families of those children can afford private treatment, they are only supported for the short list of therapies that B.C. funds, all of them with wait times sufficiently long that some children pass through the all-important early years with no support.

More than anything, Jacquie wishes she and Frank could be paid as caregivers for Emma. If Emma was in government care, her foster family would be receiving as much as \$3,000 a month for her care. But there's no such income support for parents of children with special needs.

*"We know our children best, and are the best caregivers for them," says Jacquie. "But because of the amount of care required, we can't work, and so we live in poverty. It becomes a stressful and exhausting situation. We can't get Emma the things that would help her. It would be so empowering to allow and support families to make decisions for their children."*

## Revelations from the pandemic

Community Partners echo families' concerns about the absence of flexibility in the system, adding that the lack of flexibility in their own government contracts interferes with their ability to respond rapidly to shifting family needs during a pandemic. MCFD provided some contract flexibility for the first three months of the pandemic, but our partners say such flexibility is still badly needed as the impact of COVID-19 continues.

*“The current siloed contracts and output-based contract deliverables for agencies inhibit how organizations and families do the work together,” one organization told us. “Allowing agencies to be flexible and transition funds between programs would allow for more flexibility for families.”*

The government did step up to increase service flexibility during COVID-19. For the first six months of the pandemic, families of children funded through B.C.'s autism program were allowed to spend 35 per cent of their annual allotment on equipment needs, up from 20 per cent – an important change in light of those 19,000 children and youth suddenly losing access to all the specialized equipment and therapies in centres and schools closed by COVID-19.

“The best thing they did was allow parents to sign the Justification for Equipment form, as we know our children best. This should be a permanent change. Also allowing 35 per cent of your funding to be spent on equipment. Relaxing the respite rules to allow us to use as we see fit has been helpful.”

– from RCY November 2020 survey

Unfortunately, rigid approval processes for those newly flexible autism supports placed them out of reach for the duration for many families. The time that families needed that money most was at the height of the pandemic, says one mother, but the difficult and slow approval process grew even more difficult during COVID-19.

She would have liked to have bought a punching bag for her angry and frustrated 15-year-old son, who has been in crisis since COVID-19 hit. She knows other families who were wishing for a small trampoline or a hammock – items that could stand in for the activities that kids with autism have not been able to access during the pandemic.

The family presumed they still needed a “Justification of Equipment” form signed by a registered health professional. MCFD waived that requirement for the first six months of the pandemic, but Community Partners say families and even CYSN workers weren't necessarily aware of directives coming from MCFD senior management.

The requirement is now back in place, and challenges continue. *“How do you get all the approvals when everyone is harder to get to?”* asks the boy's father.

Families supported through B.C.'s Autism Program have comparatively flexible funding compared to families whose children receive their funding through other programs. But there are many problems in that funding stream as well, says Deborah Pugh, Executive Director of ACT – Autism Community Training.

*“Families struggle to provide adequate intervention on \$22,000 a year. The fact that our families have not been able to roll over the funds from this contract year to the next during the pandemic has really angered parents. Not only did all services stop, but funding was lost, too.<sup>45</sup> And it's not like children with autism stay frozen without intervention or therapy. They get worse.”*

<sup>45</sup> Children under MCFD autism agreements who turned either 6 or 19 between March 15 and Aug. 31 were eligible for a three-month extension.

In addition to the respite issues for families noted previously, many families either didn't know that government had loosened restrictions on how funds could be used, or were unable to connect with their CYSN worker to get the approval.

The April 2020 survey of 75 B.C. families on MCFD's At Home Program found that only 12 per cent of families in the initial weeks of the pandemic had received approval from their CYSN workers for full flexibility in using their monthly respite funds, and half were still waiting to hear back from their workers. Our November survey confirms that serious communication problems have continued, with 89 per cent of families reporting no contact or very little contact with their worker since September, and 38 per cent still seeking clarity on how their respite funds can be used. RCY recognizes that the shift to flexible use of respite funding was a significant change in direction from standard MCFD policy, and that staff required time to understand that.<sup>46</sup>

Flexible approaches and policies that fit each CYSN family's distinct needs were recognized as vital by the Select Standing Committee on Children and Youth in its October 2019 report, *Children and Youth with Neuro-Diverse Special Needs*.<sup>34</sup>

After hearing from families, advocates and community organizations at eight public hearings around B.C., the committee urged systemic change.

*“One of the central issues emphasized by the Committee was the need for a child and family-centered model of care that recognizes each child's and each family's unique circumstances, and works with families to determine and provide appropriate, wrap-around supports and services.”<sup>47</sup>*



During the pandemic, a young boy in a mask prepares his stuffed horse for dental surgery.

Photo: Kristy Wolfe Photography

<sup>46</sup> At Home Program Supports Survey, April 2020; B.C. Parents of Complex Kids.

<sup>47</sup> Select Standing Committee on Children and Youth, *Children and Youth with Neuro-Diverse Special Needs*, p. 29.

## Family story – Jordan, Kurt and Jonas

When the B.C. government announced during the pandemic that families of children with special needs were going to have more flexibility in how they spent their respite funds, B.C. couple Jordan and Kurt knew in a heartbeat how they would use theirs.<sup>48</sup>

They booked chiropractic treatments. And a massage.

People don't always understand that round-the-clock caregiving for a child with severe disabilities can be back-breaking work in every sense of the word, says Jordan. Her son Jonas, now 4, has severe quadriplegic spastic cerebral palsy.

The family lives in a townhome with “a lot of stairs,” requiring much lifting and carrying of Jonas even as he grows bigger with each passing year.

*“We deal with a lot of physical pain,” says Jordan. “We spend hundreds of dollars at the chiropractor or getting massage therapy to try to prevent that pain. We have no lift, and he’s not in his wheelchair all the time.”*

Born more than three months premature, Jonas spent the first six months of his life in neo-natal intensive care units, first at a community hospital and then at B.C. Children’s Hospital. Jordan will never forget the terrifying transition from 24/7 hospital care to bare-bones supports after Jonas was discharged.

He’s the youngest of four children. All were home-schooled during the first months of the pandemic and for the indefinite future, as Jonas’s health is too fragile to risk bringing a bug home from school.

Life has been hard for the family since long before the pandemic, acknowledges Jordan. The endless need to search for other sources of funding to top up what government doesn’t cover continues to make it considerably harder, she adds.

*“When we first got into the system after Jonas was born, I felt so grateful to not have to pay for everything,” says Jordan. “But reality for parents like us is that we spend a lot of time on the phone, doing research into who funds what, pleading our case to different charities. There is so much work to do in addition to looking after Jonas. Still, I’ll fill out an application form 10 times over to avoid paying \$12,000, which we really don’t have.”*

The family receives respite and basic benefits – help with special formula and diapers – through B.C.’s At Home Program. Jordan says they usually use the \$256 a month respite funds to fly her parents out from Alberta to stay with Jonas and his siblings. But COVID-19 ended that.

There was a brief and horrifying time when Jonas was no longer eligible for nursing services and was unexpectedly dumped out of the entire At Home Program for three months. That problem got sorted out, but it still hurts Jordan to see wealthier families able to buy the kinds of therapies and supports for their children that those relying on the public system simply can’t access.

*“As I watch those who have gone with private physio make leaps and bounds in their development, it saddens me that we haven’t been able to provide that for Jonas,” she says.*

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<sup>48</sup> Names have been changed.

The irony isn't lost on her that the government invested at least \$630,000 in Jonas by keeping him for six important months in intensive care after his birth, but now provides only the most basic of support.

*"The amount available for equipment is so outdated that there's no choice but to be applying to charities all the time to help out,"* says Jordan.

The family briefly had two wheelchairs for Jonas, so they could spare themselves the hard work of hauling his chair up a flight of stairs every time they came home. But when his "inside" wheelchair broke, the family was told they could apply for a new one only once every three years. They're still waiting.

Jonas's wheelchairs each cost \$7,000, but the government contribution tops out at \$6,000 total. That left \$8,000 that the family needed to come up with the last time around to buy the essential equipment. Jordan had to apply to charities, *"all of which dragged the process out for months."*

Jordan wishes her family could afford an accessible house and adapted van for transporting Jonas. But those seem like impossible dreams most days. She wonders how other families with even less support are coping.

*"I would be one to advocate until my death for mental health supports for parents of children and youth with special needs,"* says Jordan. *"You get into the snowball of this life, and out comes substance abuse, stress drinking, isolation. I think there are a lot of families who wouldn't have the personal resources to carry on."*

## 5. Our ongoing failure to provide adequate and consistent needs-based support for CYSN families is causing long-term harm that impacts every British Columbian.

Jonas was something of a miracle child when he was born more than three months premature. He spent his first six months in neo-natal intensive care struggling for his life. Nothing was held back in terms of the medical interventions to ensure his survival.

But his parents will never forget the terrifying transition from round-the-clock ICU care to bare-bones supports after Jonas was discharged into their care. Now age 4, he has severe quadriplegic spastic cerebral palsy, a lifelong disability. The days when he received all the support he needed are long gone, says his weary mother. She is deeply concerned that his family's inability to afford private care for Jonas is jeopardizing the life he will have as an adult.

Another mother spoke of the painful reality that her wish to raise her own child means less publicly funded support than he would get if put into government care. Our Community Partners have voiced similar concerns for many years.

CYSN families consulted for this report talked about feeling like their children had been “*written off*” by government, their families provided with just enough support for their children to survive but never thrive. That was a driving concern for B.C. families of children with autism when they began fighting years ago for the right to direct their children's funding in ways that best suited each child's development.

The families and Community Partners who we consulted for this report say B.C.'s CYSN support services often feel as if the goal is to screen children out of services through rigid eligibility criteria, rather than help them reach their potential.

As previously noted, one family refinanced their house to free up \$40,000 for extra therapies for their twin two-year-old boys with significant special needs. Like every parent, the twins' parents want them to grow up to be the best they can be. They wonder why government wouldn't want the same.

*“As a parent, you feel mostly alone. Does anyone care what happens to my kids? Anyone? Not really,”* says the boys' mother.

Canada is a signatory to the *United Nations Convention on the Rights of People with Disabilities*. The principles of that convention include full and effective participation and inclusion in society; equal opportunity; and respect for the evolving capacities of children with disabilities.

That it's difficult or even impossible for children to get the supports they need from the earliest age is a breach of that commitment, say our Community Partners and the families we reached out to.

They note that a child with cerebral palsy whose family can't afford the \$1,600 a year required to top up inadequate funding for new leg braces can be expected to grow into adulthood with a higher level of disability and a lower quality of life. A child whose delayed autism diagnosis costs them critically important interventions in the early years – not to mention the window of time when B.C. funding

supports are most robust – is denied a literally life-changing opportunity that comes around only once in terms of having the most impact on a young and malleable brain.

The development of other children in the family home is also affected when a child or youth has special needs, due to the overwhelming needs of that child. That issue was exacerbated by the pandemic, when the routines and supports for neuro-typical children were also disrupted.

Families' economic productivity and ability to engage in regular community life is profoundly affected by the hours and hours of daily unpaid care required to look after their children, say our Community Partners. Forty-four per cent of the B.C. families responding to the 2019/20 survey on financial need reported household incomes below the B.C. average.<sup>49, 50</sup> The economic impact of the pandemic on families of children and youth with special needs has been significant, with 26 per cent of respondents in our November survey reporting a loss of employment and 28 per cent, a loss of self-employment. Sixty-five per cent of families faced increased costs due to school closures.

The earnings that families give up as a result of being full-time unpaid caregivers for their children is incalculable, as are the forfeited tax dollars from those lost earnings. Our Community Partners note that for two-parent CYSN households, only one parent is typically able to maintain work outside the home. For single-parent households, families' choices are to try to get by on various child benefits, look for home-based work to squeeze into spare moments in their day or apply for income assistance. *"I have had to quit my job, which was 40 per cent of our income, due to the lack of support services in school and from [MCFD],"* wrote a respondent in the November survey.

Finding work in a chosen profession isn't an option for many parents of children with special needs, say our Community Partners and the families we talked with. Instead, parents look for the kind of work that can fit into small gaps amid the round-the-clock needs of their child – work that allows them to suddenly take off a day, a week or even longer if their fragile child gets sick or needs surgery, or to drop everything to pick up their child with autism from school yet again when the child's behaviours flare.



A girl plays with her mother's fingers while they wait for her sister to finish a gymnastics class prior to the COVID-19 pandemic.

*Photo:* Krystle Schofield Photography

<sup>49</sup> Financial Survey for Families with Complex Kids, B.C. Parents of Complex Kids.

<sup>50</sup> Statistics Canada, Real Average Total Household Income (Before Taxes), 2017.

## Family story – Maddie, Stephen and Evan

You can't be too careful when your six-year-old son requires a ventilator to breathe and suddenly there's a mysterious new respiratory virus circulating all over the world.

Maddie and her husband Stephen went into self-imposed lockdown at their home on the Sunshine Coast to protect their medically complex son after the COVID-19 pandemic hit.<sup>51</sup> That meant cancelling all in-home nursing services for six-year-old Evan and providing that care themselves, though in truth Maddie says the services have been extremely difficult to find anyway for well over a year.

*"We just shut down our home entirely once the pandemic started," says Maddie. "It was my husband and I on our own, round the clock for the first month."*

*"And it's been really hard, though I'd never want to make it sound like my son is a burden, because he isn't. He is an incredible child. Unfortunately, we feel as if the system sees our whole family as a burden, especially when it can be so difficult to access the supports our family needs to thrive."*

Evan was born with a rare condition that causes severe muscle weakness. It has left him fully dependent and on a ventilator.

He qualifies for the maximum supports allowed under B.C.'s Nursing Support Services program. But being able to find available nurses to provide those services has been nearly impossible for the family since they moved away from the city to a more rural community in 2018.

That move was purely for economic reasons, says Maddie.

*"We'd finally gotten to a point with Evan in the city where we were almost there with sufficient services, but financially we were a disaster," she recalls. "We just couldn't get by in the city. On top of that, Evan has a tracheostomy, a ventilator, he's fed via a gastric tube and in a wheelchair, and we were in a tiny apartment we couldn't afford, climbing over each other and all the equipment. Finding accessible housing that was also affordable was next to impossible."*

*"We were lucky to be able to move in with my mom, but now we don't have the services. We've gone from seven nurses to two, with part-time availability. So we've been assuming all care for the past year-and-a-half. We take on a lot – we're very hands-on parents. But we still struggle with the gaps in our system."*

Stephen works outside of the home and Maddie has home-based work she fits in where she can while managing Evan's constant care needs. The family currently has many hours of unspent nursing support, but Maddie has little hope for being able to use the funds. Government has told families they won't be allowed to roll over any leftover monthly funding.

Maddie recognizes that as desperate as the situation feels for her family, other families of children with special needs have it even worse.

If Evan had all the same disabilities but didn't require a tracheostomy to help him breathe, for instance, he likely wouldn't qualify for any nursing supports under current guidelines. If Maddie and Stephen didn't have supportive parents and an understanding of how to navigate a complex system,

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<sup>51</sup> Names have been changed.



they would be on their own – just like many of the parents they have met after connecting to the B.C. Parents of Complex Kids network.

The family has been supported by some “incredible” social workers and early-intervention programs over the years, but Maddie knows from other families’ experiences that much of that is the luck of the draw.

Many families don’t even know they have a CYSN social worker assigned to them, notes Maddie, which means they also may not know what potential supports are available. CYSN social workers in B.C. typically manage caseloads of approximately 130 families.

Maddie wishes families like hers could be paid a guaranteed income to provide care for their children. That’s the case for children with disabilities who are in government care – depending on the level of disability, foster homes can receive close to \$3,000 in government support a month per child.

*“I would be happy with even \$10 an hour to stay home with my son,”* says Maddie, noting that amount would be much less than what the government funds for facilities and health-care workers.

*“We are the experts in the care of our children. We should have options and flexibility, as each situation is unique. Sometimes you almost feel like you’re being punished for wanting to keep your child rather than put them in government care. Why would you rather tear a family apart than work to keep them together?”*

Maddie echoes other families’ calls for an urgently needed update to the At Home Program, whose rates for equipment needs haven’t changed in 30 years.

*“I wish to see families like ours move out of poverty, and be supported by a program that fully pays for the equipment our children need to live and thrive with,”* says Maddie. *“It is not okay that we are begging to charities, and that charities can barely keep up with all of our needs.”*

## Life in a pandemic: We must do better

For CYSN families and community organizations, the pandemic is both a time of long-standing service gaps and inequities getting significantly worse, and of enjoying some flexibility in how services and supports were provided. *“Let’s permanently put into place the innovative service delivery models that were initiated and created as a result of the flexibility provided,”* suggested one Community Partner during our consultations.

“The flexibility has been life saving for us but we need it to continue.”

– from RCY November 2020 survey

The chance to receive up to \$2,000 a month from the federal Canada Emergency Relief Benefit wasn’t just a nice pandemic measure for exhausted and overwhelmed CYSN families, it was a revelation. The freedom to use respite funds for a chiropractic appointment or a takeout meal were small gifts to parents of complex children and youth. The sudden shift to an online platform brought many challenges, but at the same time offered glimpses of new ways to bring more services to families.

Our Office also acknowledges the tremendous efforts of so many frontline CYSN workers to continue to support CYSN families through unprecedented disruption and uncertainty. In the face of a lack of direction and an absence of policy in the initial weeks of the pandemic, these workers went out of their way to help families as best they could.

The deprivation to CYSN children caused by the widespread closure of services they relied on brings its own revelations, however, as does having COVID-19 pull the curtain back on the outdated, inadequate and deeply inequitable way we parcel out and deny essential health and social support services to CYSN families. A widespread breakdown in communications from government to these families left far too many unaware of or unable to access supports intended for them.

MCFD’s temporary CYSN Emergency Benefit of \$225 a month got off to a slow start at the beginning of the pandemic, reaching only half of the 2,672 families who were eligible. The benefit was prioritized for families deemed eligible for specific CYSN Family Support Services but not yet receiving them, but in some cases, families already receiving a service also received the benefit. However, the program was extended in July, and 2,581 families received it in that second period.

These are important lessons to build upon as the pandemic continues.

In the November survey, families identified some ongoing supports that would help their family at this time. More than half identified financial support to help cover expenses associated with their child’s disability, with 48 per cent letting us know that some form of a financial supplement that recognizes the barriers to employment would be desirable. Meanwhile, 68 per cent of respondents said flexibility in how they were able to use all funds, including respite funds, would help their family as this would undoubtedly support their decision-making as the people who know their children best.

Helping CYSN families be better prepared for the ongoing challenges of the pandemic comes down to building on what worked – increased flexibility in how supports could be used, economic supports that let families concentrate on the care of their children – and changing what didn’t.

On that latter point, it will be vital to address communication failures that prevented families from even knowing what emergency measures were available for them, or in finding alternatives when respite and

other essential support services and medical treatments for their children collapsed. *“It was like we were a complete after-thought,”* said one parent.

That communication failure also left families and community providers unable to share their experiences with anyone in government who could have taken steps to address some of the problems. Many problems and frustrations for families might have been resolved early on had the information that advocacy and community organizations were sharing been acted on by the ministries that fund CYSN programs.

Pandemic-related emergency benefits for CYSN families should be structured with maximum flexibility and the least amount of paperwork and approval processes possible. These are families carrying a vast paperwork burden in lives that are completely filled up by their children’s complex care needs and trying to earn a living, and the pandemic brought more crisis. Processes should be streamlined and rapid, with an overarching purpose of helping families address their emerging needs quickly.

Approval processes for use of funds (Autism Funding, At Home equipment needs, etc.) also need to be streamlined and reimaged under the circumstances of a pandemic. The processes that CYSN families have been expected to manage during the pandemic – getting a regulated health professional to sign off on a form for a piece of equipment, for instance – can feel impossible amid the disruptions of COVID-19.

“It is absolutely insane, the wait times for Autism Spectrum Disorder assessment, whether done through the public system or privately. My child has been on the waitlist for almost a year and the last time I called to ask about the waiting list estimate, they told me the wait time is now 18 months!”

– from RCY November 2020 survey

Some important services broke down entirely in the initial months of the pandemic. Wait times of a year or more for diagnosis and assessment were already common before COVID-19, but the process came to a full halt in the first four months of the pandemic. That not only left waiting families to wait even longer, but denied them vital pandemic-related supports meant for families like theirs because their child didn’t yet have a diagnosis.

The government’s efforts to support CYSN families who are wait-listed for respite but not yet receiving a service was a well-intended but confusing and divisive initiative. The benefit was meant to give families equal respite support regardless of whether they were still waiting for a service or already receiving it, but in truth there was scarce respite for everyone due to the nature of the pandemic, widespread failure to communicate to family-serving organizations and families as to who qualified and how to apply, and regional differences in how eligibility criteria were interpreted and the benefits were allocated.

The distinct needs of CYSN families were not sufficiently considered in B.C.’s emergency response. Declaring these families as “essential workers,” for example, would have recognized their roles as full-time caregivers and let them access special services. Special store opening hours and other arrangements for people with disabilities should be extended to include CYSN families.

*“There are so many things out of our control right now – out of everyone’s control,”* says Brenda Lenahan, of BC Parents of Complex Kids. *“Children with complex disabilities and their families are shifting to adjust to the current realities, and we desperately need MCFD to do the same. Our kids can’t wait for new frameworks and better economic times. MCFD has an opportunity to change course so families don’t hit the rocks, but they need to act now.”*

## Immediate steps recommended to ease pandemic pressures

In collaboration with our Community Partners, this report identifies changes needed for the immediate future and for the longer term, the latter of which we explore further in the “Future Directions” section below. Here are the immediate measures that our Community Partners recommend be taken in support of CYSN families, given that the pandemic is likely to be affecting British Columbia for at least another year:

### Community Partners’ To-Do List for Government

- Rapidly develop and roll out a plain-language communication strategy for MCFD, modelled on the family-engaged model used by Community Living BC during the initial months of the pandemic.
- Extend for one year (Fall 2021) all pandemic-related benefits and processes for CYSN families.
- Create a roundtable or special working table that brings together designated representatives of CYSN family networks, advocacy groups, community service providers and funding ministries for regular and routine check-ins and brainstorming on emerging needs, barriers to services and access to supports. The work of B.C.’s Social Services Sector Roundtable during the pandemic provides a model. This body must include Indigenous organizations and communities to prioritize the wellness of Indigenous children in B.C.
- Declare CYSN families “essential workers” for the purposes of allowing them to access critically important services during pandemic lockdowns.
- Work with and fund community organizations that serve CYSN families to develop activity plans for children losing school-based and development-centre-based services.
- Review virtual service provision of child development services to CYSN families during the first wave of the pandemic to identify promising practices and weak points needing improvement.
- Streamline emergency benefit and approval processes for all CYSN funding streams, with an objective of reducing families’ paperwork and confirming that all approval processes are viable even during the mass disruption of a pandemic.
- Collaborate with community public health officials and health authorities to explore whether “bubbles” can be created for in-home services such as Nursing Support Services and respite to enable families as well as service providers to limit their exposure to others during a pandemic.

## Family story – Jennifer, Nicholas and Hannah

In the strangest of ways, the pandemic has turned out to be a good thing for Jennifer and her children, Nicholas and Hannah.<sup>52</sup> It took the overwhelmed Lower Mainland family straight into the abyss, in fact. But sometimes a full-on crisis is the only way to get seen.

Nicholas, 10, was diagnosed with autism at age eight. Jennifer had been trying for that assessment for years at that point, but complex family dynamics had significantly delayed the process.

But then Nicholas spun completely out of control as the pandemic took hold. He was committed to psychiatric care after being taken to hospital four times over two weeks to deal with his uncontrolled and frightening behaviours. That turned out to be a good thing, says Jennifer.

*“During COVID, my son’s behaviour escalated so much that I got noticed,” she says. “He was committed as an in-patient. He was an unmedicated, untreated child with mental health issues, with his routines kiboshed. Just at the brink of collapse, things kicked in. But it takes going through the system at the highest level of crisis to get the support you need.”*

Nicholas’s struggles have been evident to his mother for years.

*“Since age four, there have been non-stop challenges with my son’s behaviours. He was kicked out of day cares all the time,” recalls Jennifer. “It was the school system that got things going for us. Nicholas was slapping people, defiant, the whole gamut. He was threatened with so many suspensions, missed every school field trip. I had to pick him up so many times.”*

Nicholas wore many labels before his diagnosis: conduct disorder, adjustment disorder, communication disorder. Jennifer says she always felt like her parenting was being questioned as well.

Life has been far from easy for the family. Hannah, 8, has a safety plan for when her big brother is having one of his angry outbursts: she shuts herself in her room, puts on a headset and watches a video.

But being confined in the house with each other during the initial months of the pandemic wore on everybody. Hannah was so frightened by some of Nicholas’s outbursts that she took to hiding under her bed. She’s now developing behavioural issues herself, says her mom.

Parents of children six and up who qualify for MCFD’s autism funding program receive up to \$6,000 a year to buy therapies and supports for their child. But that presumes a family can even find the supports they need, says Jennifer, noting that she even has a background in social work that ought to have helped her navigate services.

*“I’ve had the advantage in terms of understanding the system and the issues, but still I’m disadvantaged,” says Jennifer. “I’m struggling to find caregivers – they all quit. People don’t want to work with children like my son, or if they do, they want \$30 an hour for it.”*

Having a child with Nicholas’s challenges impacts the family in so many ways, notes Jennifer.

*“I’m facing eviction because of my son. There’s so much paperwork I have to do to find him help that it’s like a full-time job. I’ve lost friends because of my son’s behaviour. We need a bigger home, but it would be \$2,000 a month for what I need, and I don’t have it. There’s no help for that.”*

She urges government to “please find out the needs of our children and fill that gap,” rather than leave families to struggle. Children with special needs deserve the chance as much as any child to grow up into the best adult they can be, says Jennifer.

*“These kids are the future,” she says. “They can’t contribute to the economy if they aren’t able to work because of their disability. Can’t we just help them?”*

<sup>52</sup> Names have been changed.

## Toward a better future

These short-term solutions do not address the inequities entrenched in the CYSN supports that existed long before COVID-19 inflicted such misery. We urge government to seize this moment to finally address a severely dysfunctional – and even cruel – system that is failing children with special needs and their families.

Every CYSN funding stream comes with a complex back story. Some were implemented as an alternative to institutionalization of children with disabilities and complex care needs. Some came about so children with chronic health concerns could be cared for at home rather than in hospital. Some were brought about at the political level or through court decisions, or to keep B.C. roughly on track with a growing global commitment to inclusion and Canada's own commitments in documents such as the United Nations conventions on children and youth, and persons with disabilities.

As could be expected from such a varied history, the result is a piecemeal collection of services that are notoriously hard to get and infamously insufficient even when a family does qualify. Many don't. Services are starkly inequitable and not tied to a child's actual functional needs. Families of children whose diagnoses do not qualify them for support are left without help even when their needs are poignantly visible.

To have a child with special needs is to be immersed in a world where it is all too common to be turned down for truly vital supports. It's a world in which families have to constantly plead their case and beg for charity. Frequently, they must give up any professional dreams of their own due to the demands of their caregiving schedule.

For many CYSN families, there is no down time, no ability to engage in their communities or in recreational pursuits like any other citizen. The common dreams of any British Columbian – a good education for your children, a bright future for them, and even a rare night or weekend off – are tragically elusive for so many CYSN families. Facing tremendous challenge, these families are tireless and committed advocates for their children and the well-being of other children and youth with special needs. They are calling us to action.

Families without the resources for private therapies and specialized equipment live with an additional weight on their hearts: the knowledge that their children would qualify for more supports if they were in government care.

The At Home Program in particular appears to have strayed far from its philosophy of inclusion. It was created 30 years ago as an alternative to institutionalizing B.C. children with complex disabilities and support needs, and meant to move all the support those children had been receiving in institutions into their communities.

That type of support never happened. Unindexed to inflation and still stuck in 1989 in terms of almost every funding level, AHP bears little resemblance to what was promised to British Columbia families in the years when B.C. was closing down institutions and assuring concerned families that they would be well-supported in caring for their children at home. Our Community Partners tell us that much the same has happened with the Autism Funding Program.

*“When we look at this through the lens of history, the original vision of community inclusion has never been realized,”* says Karla Verschoor, Executive Director of Inclusion B.C.

What are B.C.’s goals for supporting CYSN families? Are we achieving them? Are the medical/social categories we divide children into for the purposes of funding resulting in greater inclusion and fair treatment for all, or is a primary focus on cost management denying children the therapeutic and educational support they require to reach their potential? *“Ask what we need,”* wrote an Indigenous respondent to our November survey. *“Make sure we’re informed. Let us speak instead of punishing us and being racist.”*

“The failure of providing adequate care and support to these children/youth actually involves 3 ministries (MCFD, Ministry of Health and Ministry of Education) with each wanting the other ones to pay. We would support the province to create a working committee to assess and address the chronic intra-ministry conflicts that prevent distribution of adequate care and support services.”

– from RCY November 2020 survey

Perhaps the bigger question is around what our Community Partners tell us is the long-standing failure of a top-down, diagnosis-based system to support the diverse needs of families raising children with special needs. That is a question that has been raised by those families and our partners many, many times over decades. The pandemic has confirmed that this crucial central issue must be addressed, and most especially for families who are already impacted by low incomes, race and other social and cultural factors.

The COVID-19 pandemic has changed the lives of children and youth with special needs for the foreseeable future. As the pandemic continues, with no known certainties about a vaccine and with families continuing to deal with the many hardships outlined in this report, simply going back to the way services were delivered pre-pandemic is unacceptable. RCY and our Community Partners acknowledge that pre-pandemic, MCFD committed to the development and implementation of a new CYSN service “framework” that, once implemented, is intended to transform the system to one where services are based on functional needs rather than diagnosis alone.

But a new framework will not accomplish any meaningful change if implemented within the context of a fixed budget envelope that already falls well short of meeting the needs of the CYSN families it serves. If the current CYSN budget allocation remains constant and the new framework is implemented without consideration of the ongoing impacts of the pandemic, there will be an inevitable zero sum game of winners and losers among CYSN families, with the true needs of these families not being met.

Thank you for the opportunity to share the experiences, community research and collective wisdom of our Community Partners, B.C. families, and our own Office on the profound impact of the pandemic on services and supports for children and youth with special needs.

We cannot imagine any British Columbian not being moved by the stories and concerns we are sharing here. Together with our Community Partners, we look forward to an engaged, informed and family-centred response from government that will ensure vital supports for all families of children and youth with special needs and community organizations throughout the pandemic – and a better future for the tens of thousands of B.C. children and youth who are counting on all of us for humane, equitable and needs-based supports.

## Representative's position

As this Office noted in *Alone and Afraid*, there is an urgent need for MCFD to undertake a comprehensive assessment of the actual demand for CYSN services across B.C., and the capacity of the current system to meet those needs. The revelations of the pandemic highlighted that urgency. **I therefore strongly urge an immediate re-engagement of Community Partners on the design, development and implementation strategy for the new CYSN framework.**

We identify the following problem areas for attention:

- The absence of needs-based assessment processes and eligibility requirements in all CYSN services and supports, including for children and youth with FASD.
- The lack of ongoing income support for CYSN families unable to participate fully in the paid workforce due to the care needs of their child.
- Significant inequity in supports/services based on arbitrary lines that discriminate against children who do not fit into the restricted eligibility categories for support, including children and youth with FASD.
- Chronic delays in diagnosis and assessment.
- Inequities in the At Home and Nursing Support Services programs that prevent CYSN families from accessing funding for treatments, therapies and equipment required to meet their children's diverse needs, and that risk pushing families into placing their child into government care.
- The exclusion from funding supports of families of children and youth with special needs solely because their diagnosis/need is not recognized by the current CYSN funding structure.
- The disproportionate impact on CYSN families who are also Indigenous or Black, families of colour, newcomers and refugees, low-income or single-parent.





A precious moment in the day  
for mom and son to connect  
on a walk by the river.

*Photo: Janice Hayward*



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