

## BC Family Survey - Children and Youth with Special Needs Report, April 30, 2020

Our organizations hear regularly from families who struggle with accessing funding and services for programs offered through the Ministry of Children and Family Development as well as other programs. This survey was put together in response to an increase in advocacy calls to all of our organizations with regard to Children and Youth with Special Needs (CYSN) funding.

The intent of the survey was to find out how families are coping with the extra pressures caused by COVID-19, and to hear about their experiences accessing emergency pandemic funding and/or services for their child or youth with disabilities through MCFD's CYSN program.

### Who did we ask, and how?

This survey was distributed to our networks via email newsletter and across social media. It ran for 2 ½ days, from 3 pm on Thursday, April 23rd to midnight on Saturday, April 25th.

**1055** parents and guardians of children and youth with disabilities/special needs residing in BC responded to the survey during the short time that it was open.

These parents and guardians are from every region served by MCFD.

### **Our Recommendations:**

1. Provide broad flexibility in the use of funds families receive through different CYSN programs during the pandemic, following a family-centred approach.
2. Support the resilience of families by easing their financial burden. Provide \$525 per month (to be used at the family's discretion) for the next 3 months to support families to stay strong and together.
3. Clear communications
  - Provide clear, written guidelines around emergency pandemic measures and supports
  - Ensure effective, clear and responsive communication from social workers.
  - Publish explicit health and safety protocols based on recommendations from the Public Health Officer to allow families to access in-person supports.
4. Recognize the many families of children and youth with disabilities left out of the CYSN funding structure and provide them with financial and other types of support during the pandemic.
5. Work in collaboration with the Ministries of Finance and Social Development and Poverty Reduction to introduce the Child Opportunity Benefit earlier – May 1, 2020.

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Q5 What region of British Columbia do you live in?

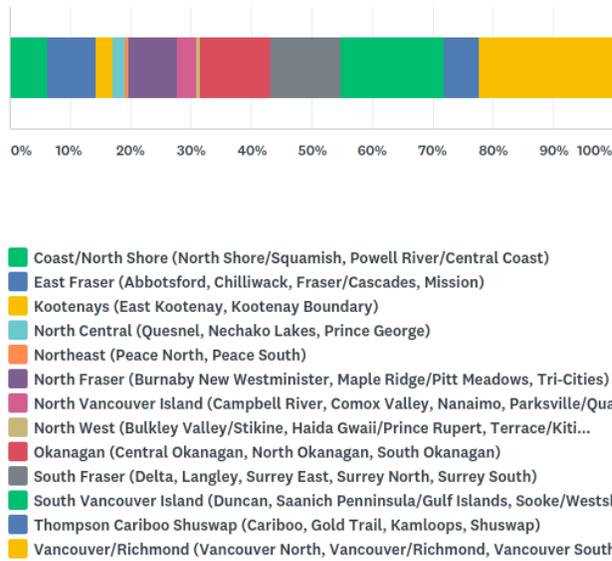


Figure 1 - Question 5 - What region of British Columbia do you live in?

Nearly **20%** of respondents were from single adult households, and **112** respondents shared that their child identifies as Indigenous.

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### Major findings:

- Nearly **60%** of families responding have not been able to access any of the MCFD emergency pandemic measures as referenced in the following announcement:

<https://news.gov.bc.ca/releases/2020CFD0043-000650>

Q14 Which of the following have you been able to access? Check all that apply.

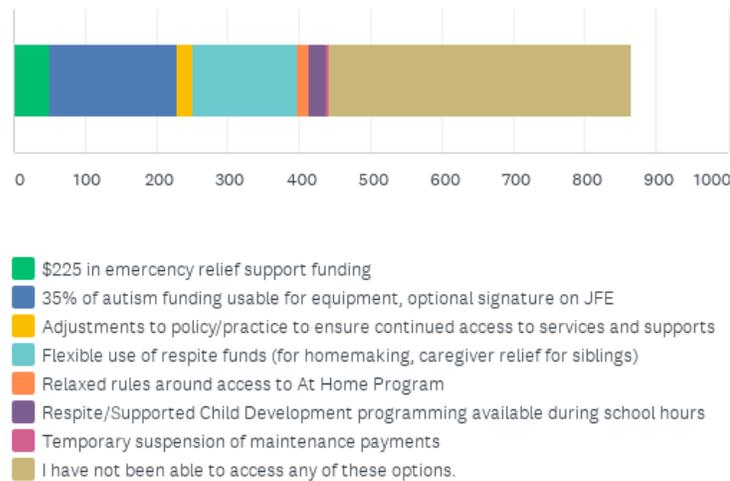


Figure 2- Question 14 - Which of the following [emergency measures] have you been able to access? Check all that apply.

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2. Nearly **70%** of families responding who have regular access to respite funds (not including the Emergency Relief Support Fund) have not been able to use those funds during the pandemic.

Q17 Have you been able to use your respite funding during the pandemic?

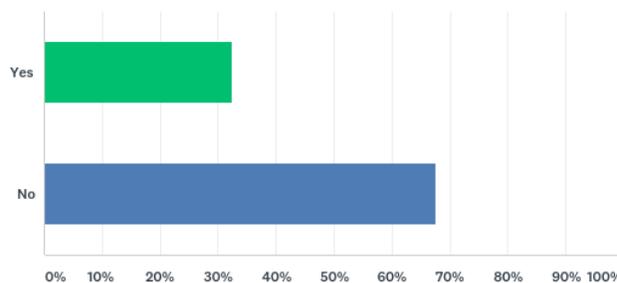


Figure 3 - Responses to Question 17 - Have you been able to use your respite funding during the pandemic?

Some respondents elaborated on using their respite funding during the pandemic:

*I have wonderful care providers who are still willing to work for us. However, it's insanely expensive, as my son requires 2:1 supports to be safe (so \$45/hr for care).*

*Only 1 time it is a difficult thing and not sure if sending my son to respite correct thing to do regards social distancing , but need more than normal*

*Respite is provided through MFCD, paid directly to respite worker. Due to covid we have no respite service and no access to the funds for any other help.*

*No, we are so far down the waiting list that we don't have a chance. Were told somebody needs to move out of the area, age out and die before we will ever be able to access the funds and services from the ministry*

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3. We asked families what they need right now, offering the following options and the opportunity to add others.

- Clarity on how respite funds may be used
- Culturally informed services
- Financial support to cover expenses associated with my child's disability
- Flexibility in use of funding (school age therapy, autism funding, behavioural consultant, counseling)
- Mental health support
- Regular communication and connection with a social worker
- To know whether I am eligible for any pandemic supports

Q25 What do you need right now during the pandemic? Check all that apply.

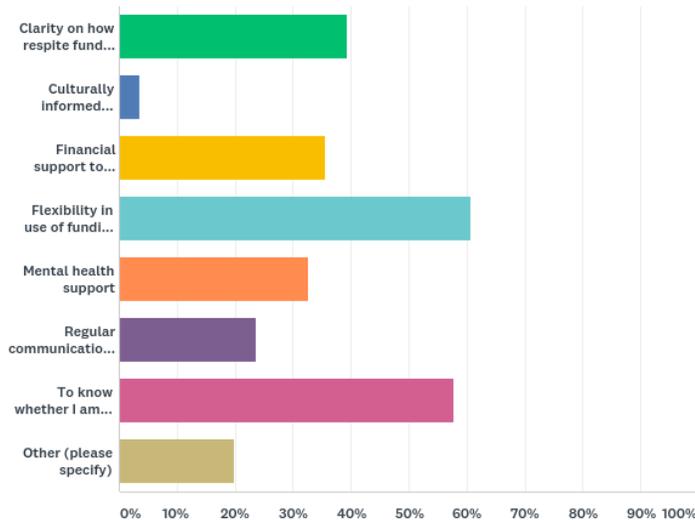


Figure 4 - Question 25 - What do you need right now during the pandemic? Check all that apply.

### The top 4 needs:

- Flexibility in use of funding – **60.6%**
- To know whether I am eligible for any pandemic supports – **57.8%**
- Clarity on how respite funds may be used – **39.2%**
- Financial support to cover expenses associated with my child's disability **35.6%**

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These are some responses from families who chose to add other needs.

*He needs counselling for managing anger and stress*

*Any help to stop my daughter hurting herself or us and to stop being in the hospital...we have been admitted multiple times DURING COVID*

*The \$225 should be allotted automatically to families. There should be no extra hoops to jump through to access that money. Care-givers and social workers are struggling already. Why make more work for any of us?*

*To be able to roll over unused autism funding into the next year because therapy services are not available right now. We will need the funding to catch up with therapy after social distancing measures are lifted.*

*To actually qualify for help. To be judged by my child's needs, not our families income.*

*Need to be able to have some sort of face time or Skype to see my son in full time care...I only receive photos and call the house to get reports from time to time....and only receive emails from the site nurse...*

4. Respondents were asked about their interactions during the pandemic with their social worker and the responses were varied. Here are just a few examples:

*Our CYSN SW is well informed, knowledgeable, and still there for us - working from home. That's encouraging.*

*She responded quickly but only with an attachment of official government statement which was vague. I feel they SNSW don't have the details themselves.*

*My social worker mentioned that only 9 of his 200+ family case load could receive the emergency funding.*

*The social worker has not been in contact for years .... he has ignored all emails and messages*

*She never provides any info, I always have to ask and she always makes it feel like I'm begging for money. I was told in response to accessing emergency funding that there are palliative families that require the money more. Why is one family with special needs more important than another? I have a 3 year old in a wheelchair that requires help with everything. My physically body cannot handle all that is required (lifting up and down stairs, moving him etc)...*

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*I haven't been contacted which gives me a sad feeling . She must be overwhelmed. I had no idea there were resources available.*

*My social worker reached out to me about respite contract and told me about using respite money for other services. I shared my families struggles around grocery shopping and she was able to access emergency funding for us.*

### Discussion and Recommendations

We appreciate the fast response we received from a large number of families. Respondents to our survey are families who have access to technology and social media. How many more families – who do not have this access - would have responded if we had been able to distribute the survey to them in a different way?

From the families responding who receive CYSN support, **55%** were not receiving respite funding before the pandemic. These are the people the Emergency Relief Support Funding was meant to help. However, when we asked which of the emergency measures families were able to access, only **6.8%** said they were able to access the \$225. **Only 50 families out of 1055.** The measures that are meant to support them are not working for these families.

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Q22 Does your family qualify to receive the emergency funding of \$225?

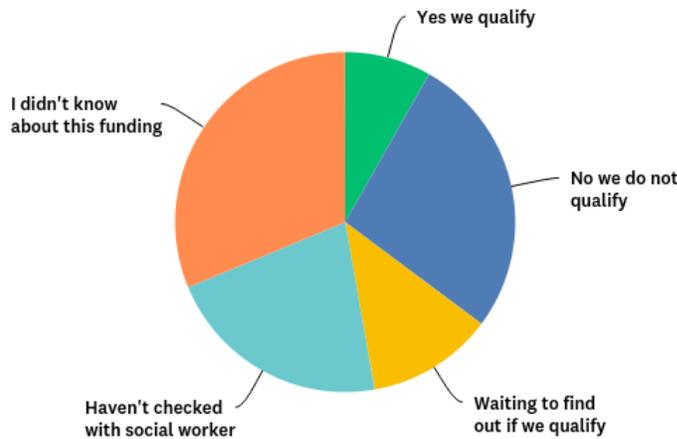


Figure 5- Question 22 - Does your family qualify to receive the emergency funding of \$225?

In addition, nearly **70%** of those who already had respite funding before the pandemic said that **they have not been able to use it during the pandemic.** More flexibility is needed.

Our organizations received 285 requests for advocacy support just from this survey, in addition to the many calls and messages we have been receiving since the beginning of the pandemic. **86%** responded no to the question “Do you feel that your family is receiving care and support that is trauma-informed during the pandemic?” Families who were already under enormous pressure before the pandemic are in need of crisis support.

The fifth most common response to “What do you need right now during the pandemic?” was that families need mental health supports, at **32.7%** of respondents. This speaks to the challenges of the pandemic but also to the impact that inadequate supports is having on families.

The pandemic is, according to respondents, amplifying the vulnerability of Indigenous families, reinforcing the need for a more intentional, culturally safe and responsive approach to providing support to all Indigenous families, and especially in remote and rural communities.

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We also want to acknowledge the **104** respondents who do not have a child who qualifies for CYSN services but were given an opportunity to tell us about their experiences with MCFD during the pandemic. Here are a few of their comments:

*We have never received any kind of services other than what we can get at school, so that means nothing during the pandemic. It is frustrating to be constantly left out of receiving help, especially as a single parent*

*I've had multiple case workers over the years. One social worker who went above and beyond to help and support and others once my family never ticked the right boxes we were left with no support. My son had a genetic mutation so rare it isn't named yet and therefore doesn't tick any boxes. Even though it looks like autism and comes with other delays. So frustrating without a "soul can label". So sad to see not only my family fall through the cracks but so many other "grey area" kids.*

*My son is a category D at school and was only attending part days with an ea. This was all the assistance I received for my child. Previous requests I have made to the ministry have resulted in minimal support and the ministry is quick to close my file. While my son is not diagnosed with autism his disabilities are severe and have significant impact on our family unit. What little support I did have before covid is all gone.*

*My child with severe ADHD, anxiety and ODD is very difficult. There are no services for us before the pandemic and I wish this would change. Our family is falling apart with ruined relationships. I fear for what the future holds.*

*I hear that MCFD is cutting funding to the early hearing program and that Deaf Children's Society will soon close due to lack of money. DCS has allowed my Deaf child to access their online preschool during the pandemic and that has been a huge support to our family as oral classes (mainstream kindergarten) by Zoom are quite frustrating for children with communication challenges, plus her school SLP services were cancelled. Finally the media is using ASL interpreters to ensure that Deaf Canadians are included in emergency planning, yet at the same time, the province of B.C. is about to force the closure of the only ASL preschool in the province. Many deaf children will now be without communication until they start kindergarten.*

*The families who were already falling through the cracks are at a complete loss. My child with ADHD, SPD and DCD will NEED access to services including physiotherapy, occupational therapy, and counseling when things return to "normal" whatever that is. The loss of the tools we were using in place of funded services (recreational swim lessons, dance, gymnastics, teacher and class supports with social challenges etc) has been devastating to physical development and mental health.*

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