

# UNDERSTANDING THE IMPACT OF COVID-19 ON FAMILIES OF AUTISTIC CHILDREN IN BRITISH COLUMBIA

REPORT – DECEMBER 2020



# COVID-19 Report

## Acknowledgements

### Authors:

- Vanessa Fong - PhD Student, Simon Fraser University
- Dr. Elina Birmingham - Simon Fraser University
- Dr. Grace Iarocci - Simon Fraser University

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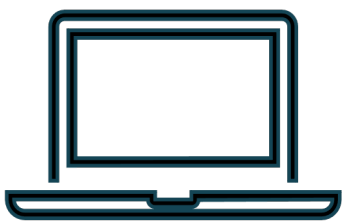
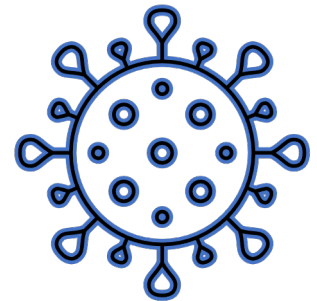
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# Survey Context

Families caring for autistic children frequently experience high levels of stress and strain due to the behavioral and learning challenges their children face. Before COVID-19, families reported lower family quality of life compared to typically developing children, children with Down syndrome, ADHD, and medical conditions such as cystic fibrosis (Bouma & Schweitzer, 1990; Brown et al., 2006; Lee et al., 2008).

The COVID-19 pandemic has only exacerbated this situation due to families being isolated and cut off from essential government support services. Parental employment changes, school closures, and a loss of services has exacerbated stress in already burdened caretakers of autistic children.



We collaborated with ACT- Autism Community Training (ACT), the Social Attention Group in Education (SAGE), and the National Autism Research Center of Israel to understand the specific needs and experiences of families during COVID-19. An online COVID-19 survey was co-created with our collaborators assessing mental health, family functioning, quality of life, and service satisfaction. In June 2020, we invited caregivers of children and youth living in British Columbia to participate in our survey.

Identifying specific challenges that impact FQOL and access to services will help provide more relevant recommendations to inform policy and practice to support families during COVID-19 in British Columbia.



# Key Terms

## Abbreviations

<b>ASD</b>	Autism Spectrum Disorder
<b>TD</b>	Typically Developing
<b>COVID-19</b>	Coronavirus disease

## Terminology

<b>Caregivers</b>	Caregivers were defined as those whose primary role was caring for the autistic child or youth.
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## Language Statement

Throughout this report, we use identity-first language (e.g., autistic individual) rather than person-first language (e.g., individual with autism) to recognize language preferred by many autistic people (Kenny et al., 2015). There is emerging evidence that this practice may help to reduce stigma (Dunn & Andrews, 2015).

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## 1.1 Respondents

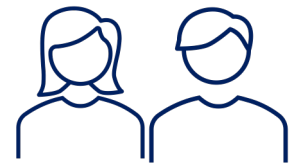


The total number of caregivers who completed the survey was **238**

### Caregiver Characteristics

#### AGE

- Caregivers ranged between 25-64 years
- The average age was 42.82 years



#### GENDER

- 93% of caregivers identified as female
- 6% of caregivers identified as male
- <1% of caregivers identified as non-binary

### Child Characteristics

#### AGE

- Children reported on ranged between 2-18 years
- The average age of children reported on was 10.47



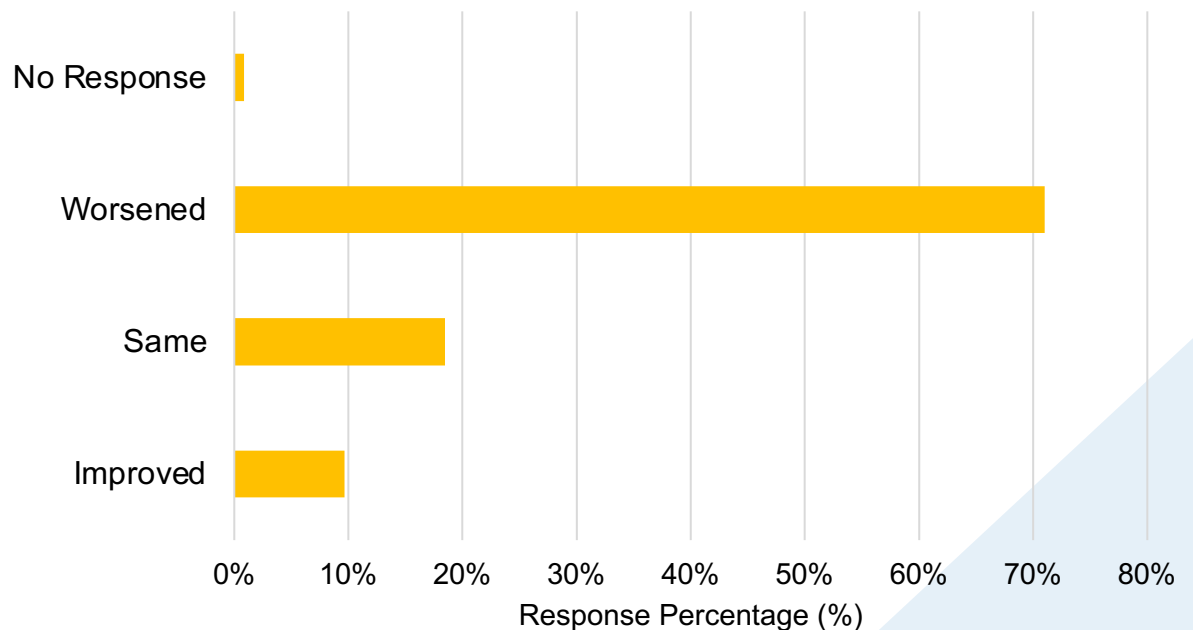
#### GENDER

- 76% of children were identified as male
- 21% of children were identified as female
- 3% of children were identified as non-binary

## 2.1 Mental Health

Over **70%** of caregivers reported that their child's anxiety has worsened during COVID-19

*“How has COVID-19 impacted your child's anxiety levels?”*



*“Both of my boys started self-harm/self-injury behaviours because of COVID-19 stress and not having their regular routine and supports.”*

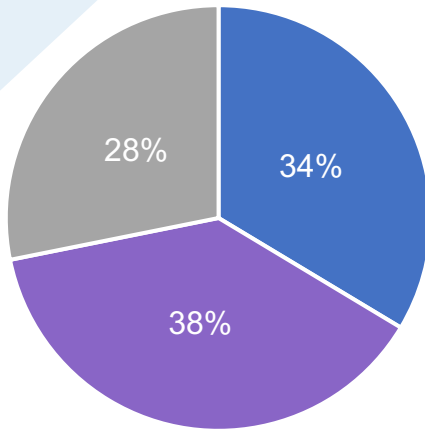
*“He became physically aggressive and violent as well as starting to threaten to harm himself. I had to do suicide assessments on my own child.”*



2.2 Child Behaviours

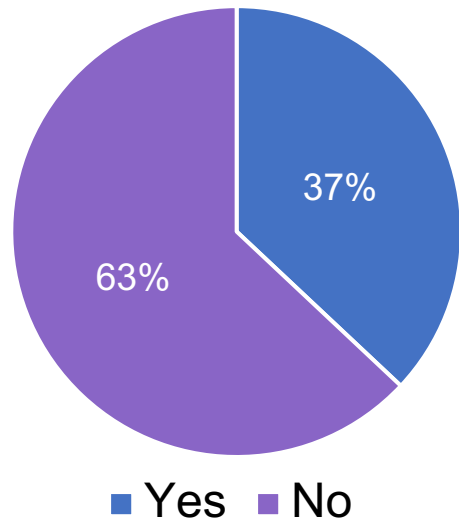
AGGRESSION

“Has your child’s aggression worsened due to COVID-19?”



■ Yes ■ No ■ No Response

“Are you worried that your child may physically hurt a family member?”



■ Yes ■ No

Almost **40%** of caregivers were worried their child would hurt another family member

“My son experienced a substantial **escalation in problem behaviours**, including physical aggression during this time but we had considerably **less access to supports and services**. This negatively impacted our family.”

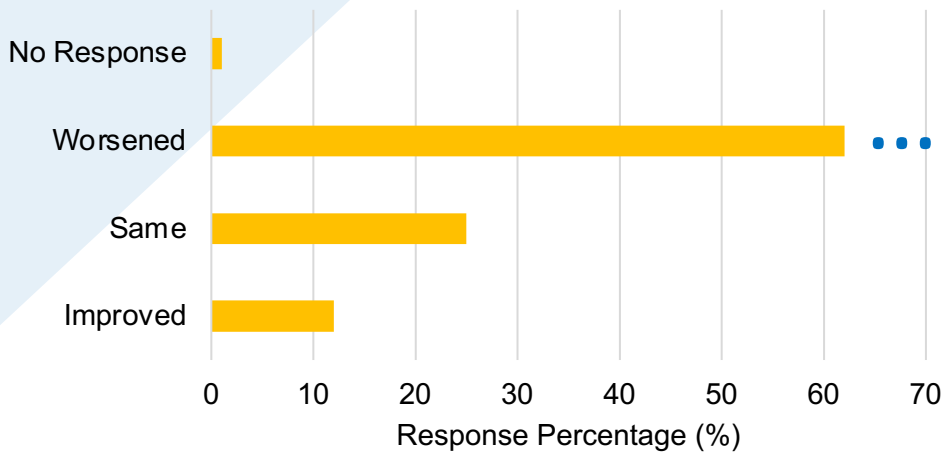




2.2 Child Behaviours

TANTRUMS

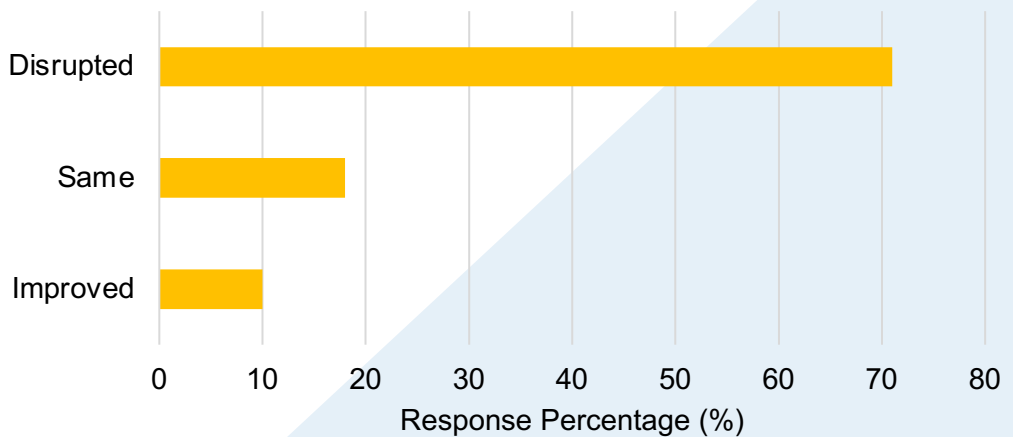
*“Has there been any change in your child's frequency and severity of tantrums?”*



Over **60%** of caregivers reported that the frequency and severity of tantrums has worsened

COPING WITH CHANGE IN DAILY ROUTINE

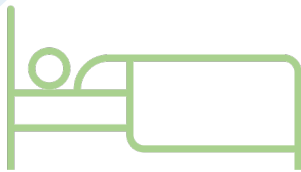
*“How has your child coped with change to their daily routine?”*



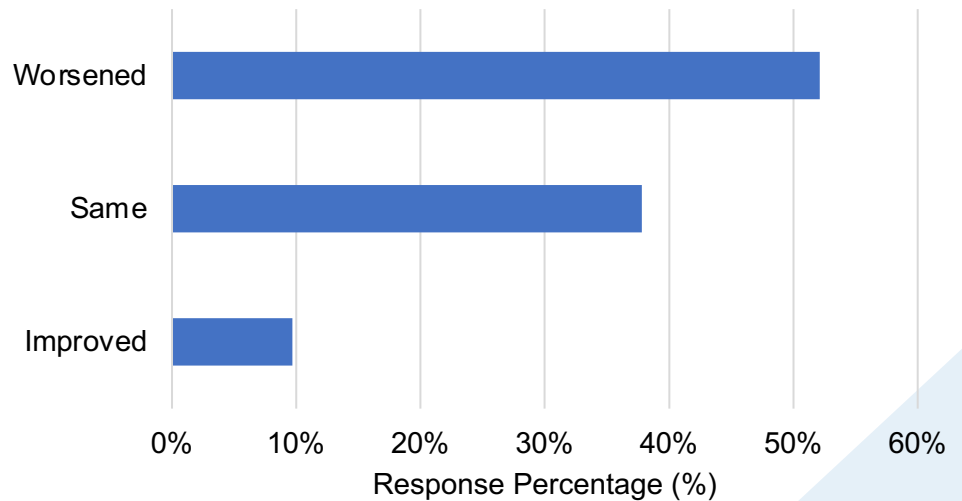
## 2.3 Sleep

### SLEEP

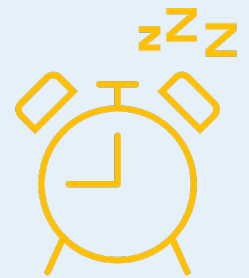
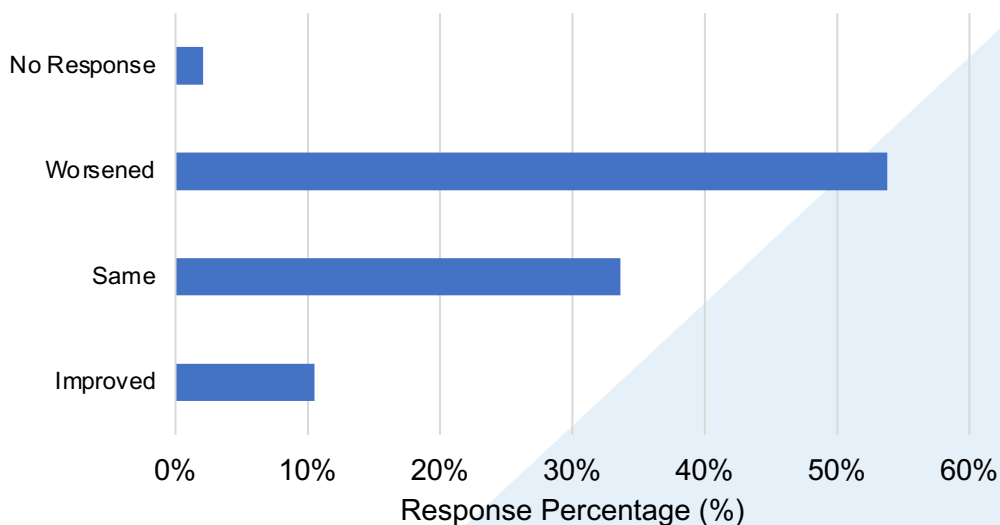
Over **50%** reported their child's sleep quality and quantity to have worsened during the pandemic.



*How has COVID-19 impacted your child's sleep quality?*

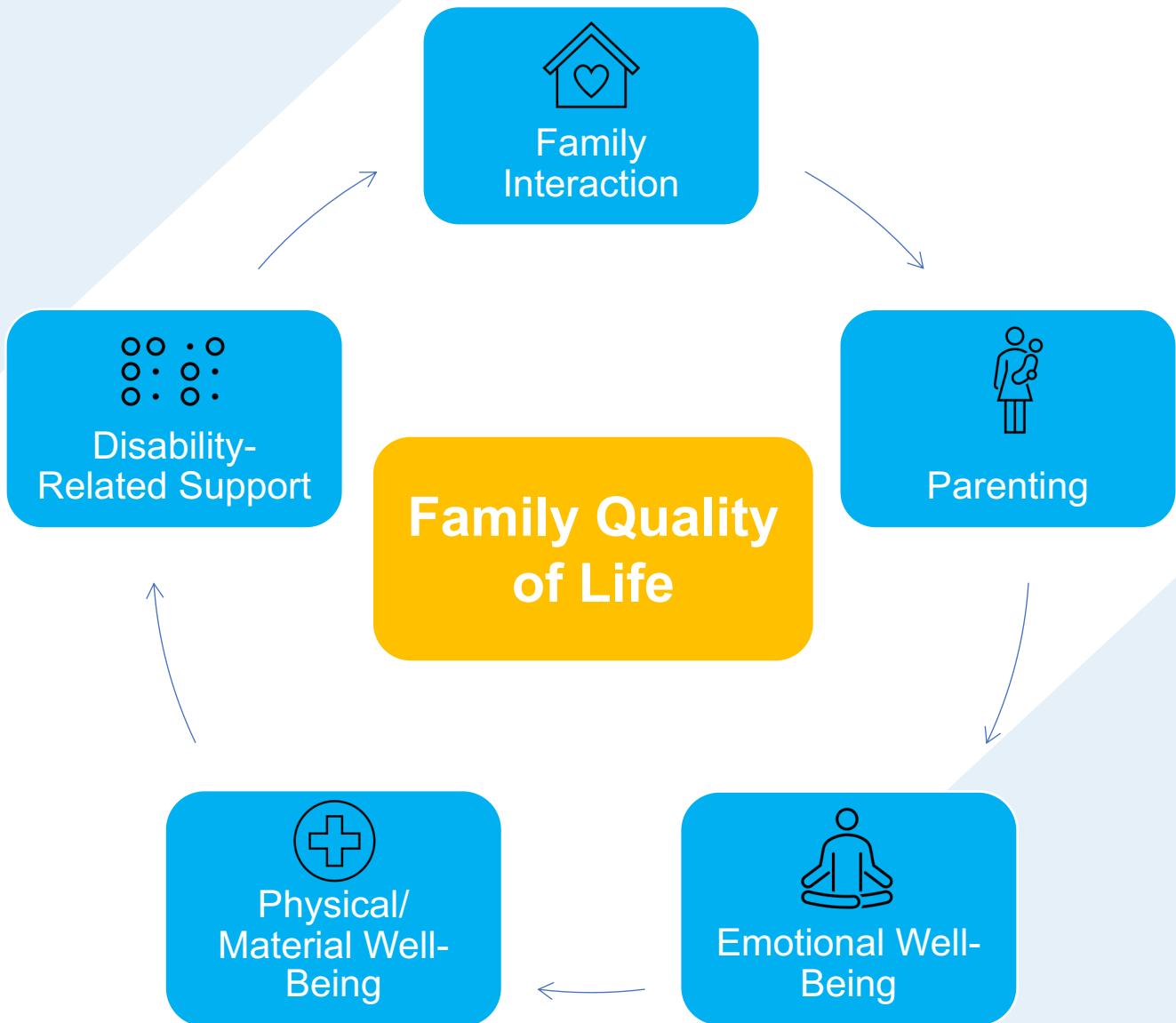


*How has COVID-19 impacted your child's sleep quantity?*



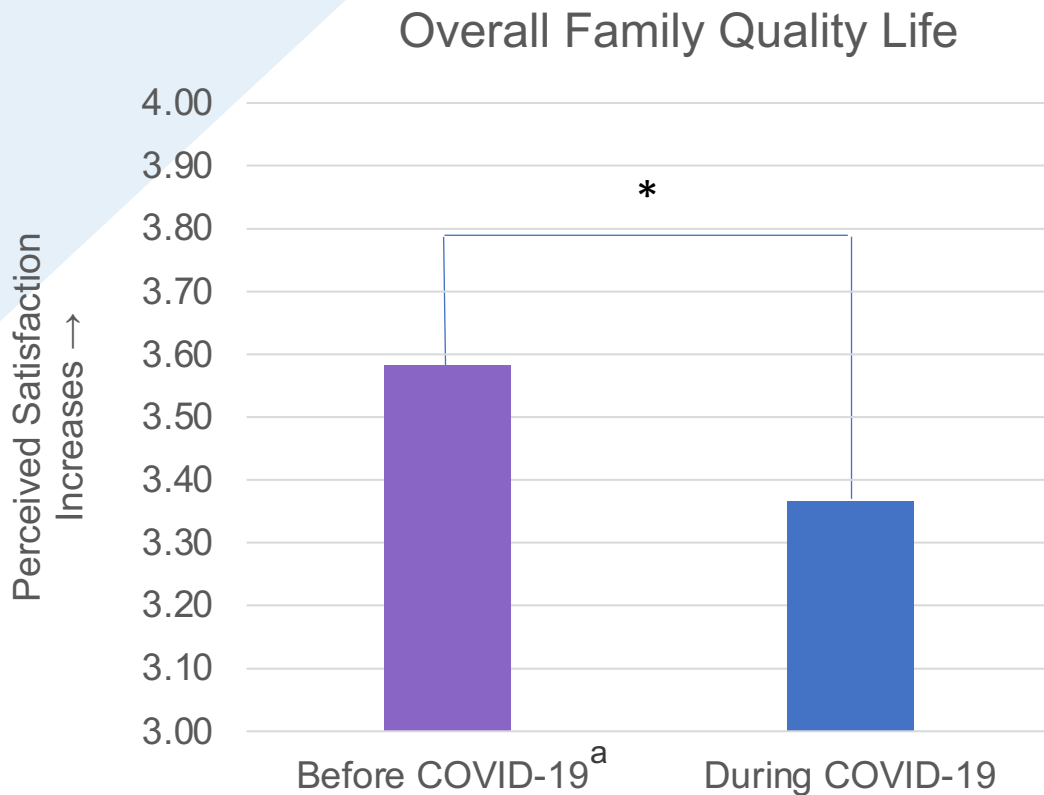
## 3.1 Theoretical Framework

### BEACH CENTER FAMILY QUALITY OF LIFE SCALE



## 3.2 Overall Family Quality of Life

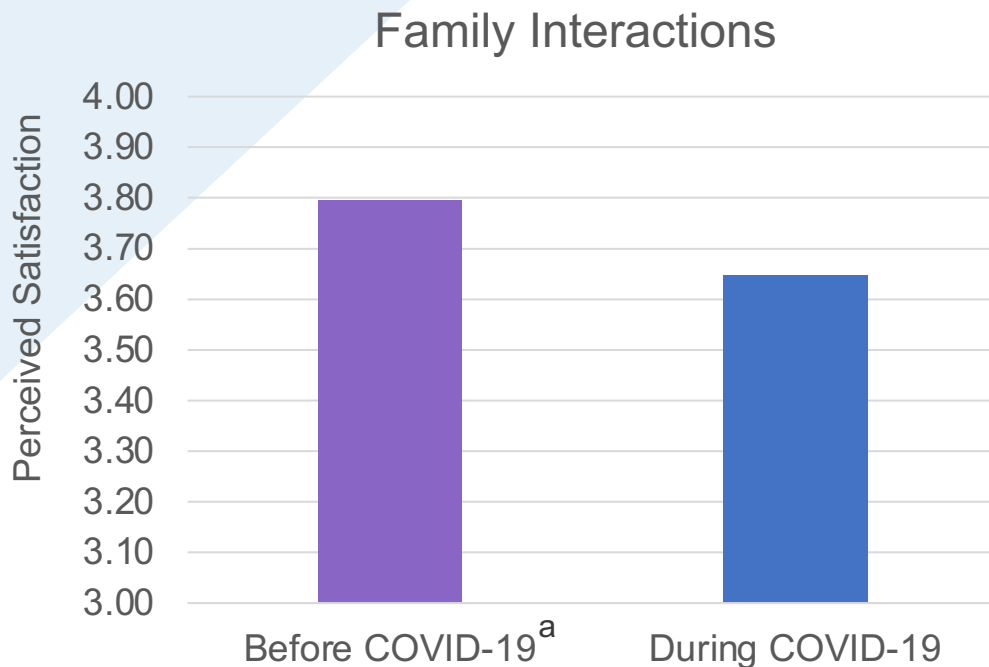
### COMPARISON OF FAMILY QUALITY OF LIFE PRE-COVID AND DURING COVID-19



Families during COVID-19 report **significantly lower** family quality of life scores compared to families sampled before COVID-19 across all 5 domains (family interaction, parenting, emotional well-being, physical/material well-being, and disability-related satisfaction).

<sup>a</sup> Data for this sample (Before COVID-19 group) comes from a study by Gardiner & Iarocci (2018). This sample is comparable to the current sample given families were also living in British Columbia with an autistic child under 18 years. However, the groups were not matched on parent education and family income, therefore these comparisons are preliminary and should be interpreted with caution.

## 3.3 Family Interactions



### SCALE ITEMS

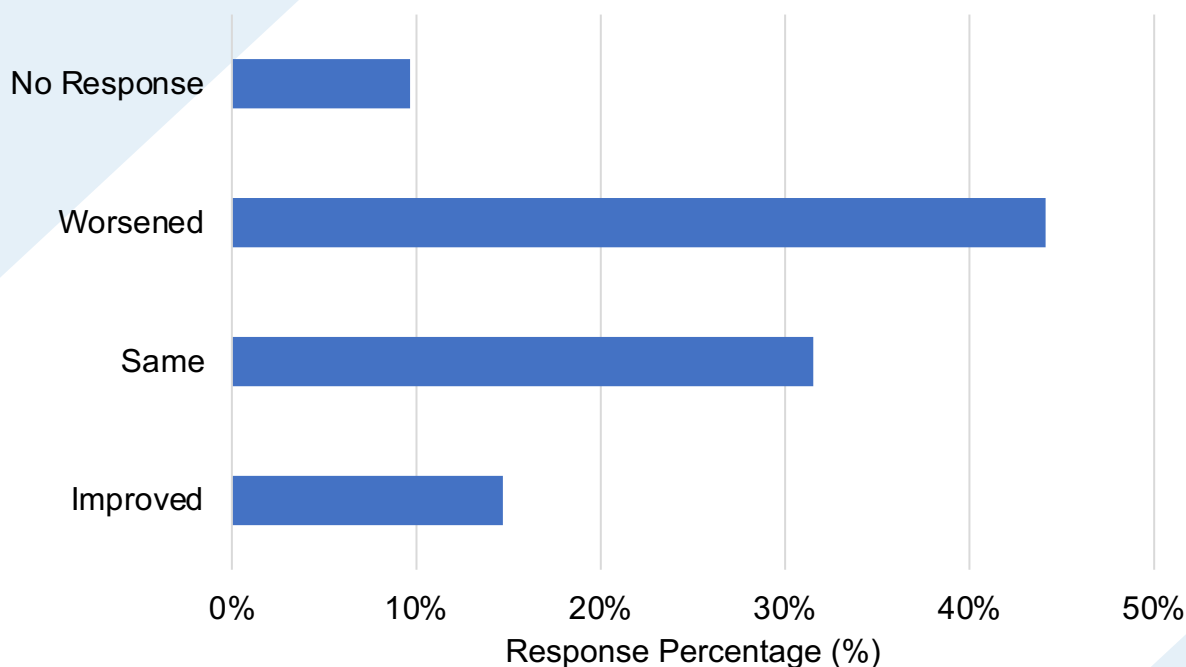
- My family enjoys spending time together.
- My family members talk openly with each other
- My family solves problems together.
- My family members support each other to accomplish goals
- My family members show that they love and care for each other.
- My family is able to handle life's ups and downs



<sup>a</sup> Data for this sample (Before COVID-19 group) comes from a study by Gardiner & Iarocci (2018). This sample is comparable to the current sample given families were also living in British Columbia with an autistic child under 18 years. However, the groups were not matched on parent education and family income, therefore these comparisons are preliminary and should be interpreted with caution.

## 3.3 Family Interactions

*How has your relationship with your spouse changed since COVID-19?*

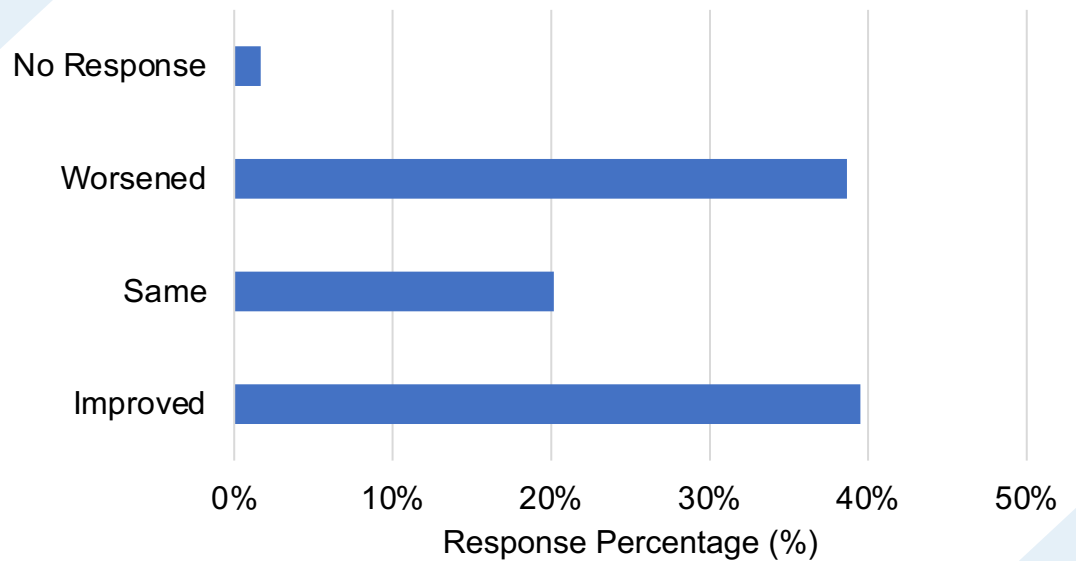


*“The risks to our already strained mental health situation and strained marriage I strongly believe outweighs the risks associated with COVID-19.”*



## 3.3 Family Interactions

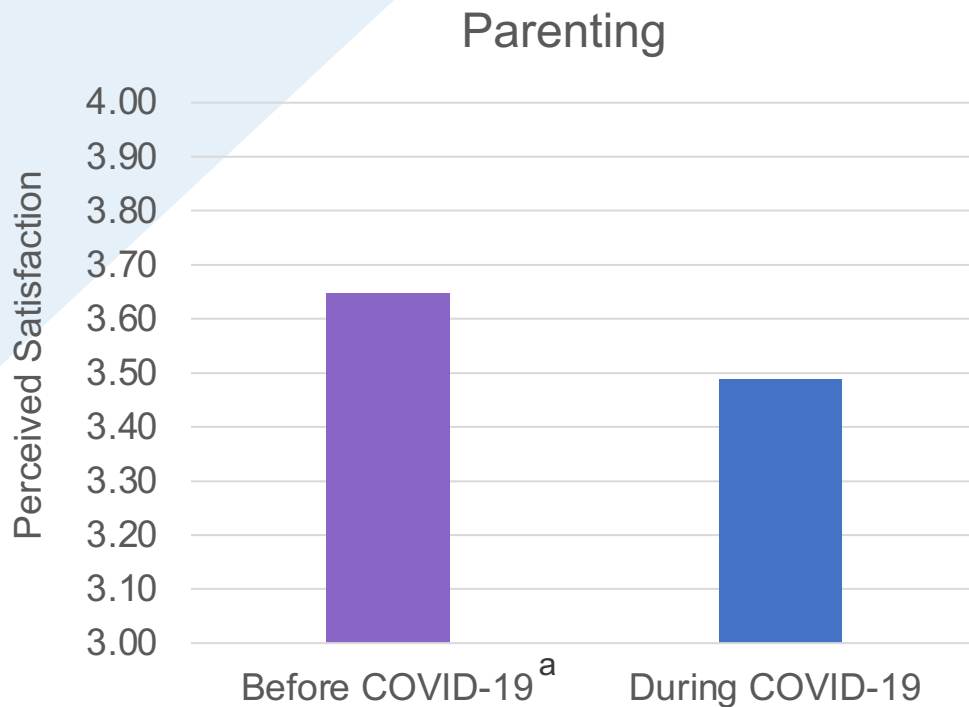
*How has the quality of time spent with your child changed since COVID-19?*



*“It’s a decline in quality of life for all of our family members. I could not keep up with work or parenting and the only way I could manage to make it through most days was to plug my kids into video games and social media for hours on end.”*



## 3.4 Parenting



### SCALE ITEMS

- Family members help the children learn to be independent.
- Family members help the children with schoolwork and activities.
- Family members teach the children how to get along with others.
- Adults in my family teach the children to make good decisions.
- Adults in my family know other people in the children's lives (i.e. friends, teachers).
- Adults in my family have time to take care of the individual needs of every child.

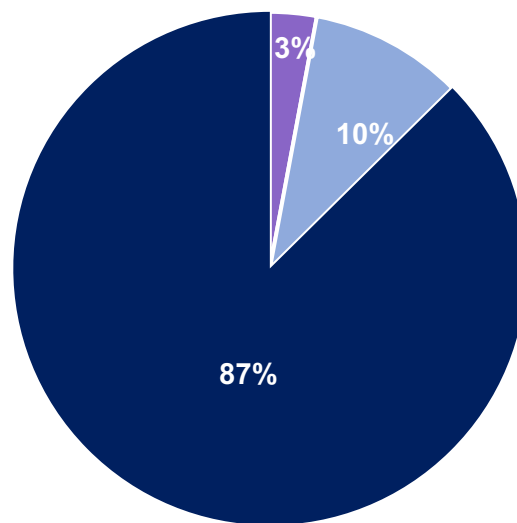


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## 3.4 Parenting

*“Since the beginning of the COVID-19 outbreak, has at least one parent remained at home regularly?”*

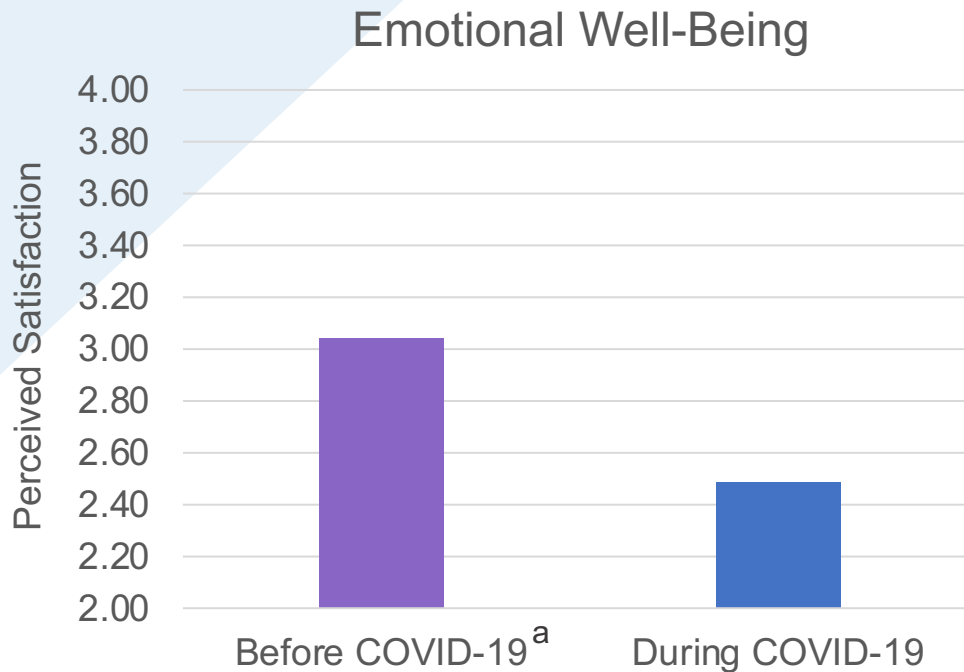


■ No   ■ Partially   ■ Yes

*“I have worked as an EA in the past and enjoyed it immensely but the pressures of working full time from home while simultaneously parenting and teaching were debilitating. If our children completed even one small school task in a day, it was all we could reasonably expect with the resources we had available to us.”*



## 3.5 Emotional Well-Being



- ❖ Out of all the family quality of life domains, this domain was rated the **lowest** by caregivers.

### SCALE ITEMS

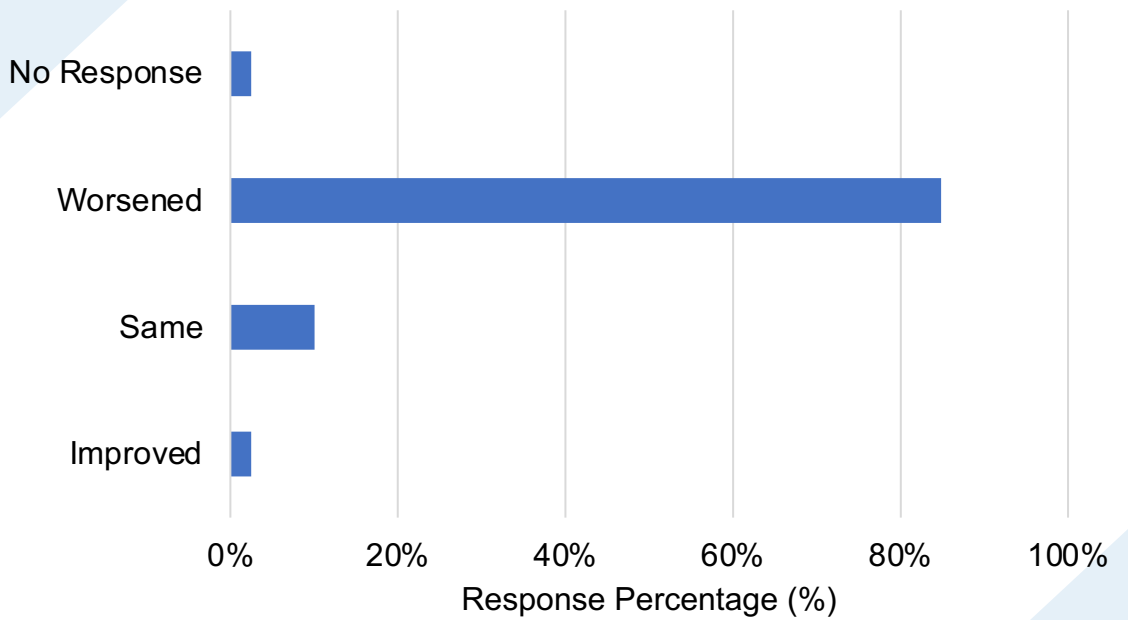
- My family has the support we need to relieve stress.
- My family members have friends or others who provide support.
- My family members have some time to pursue their own interests.
- My family has outside help available to us to take care of special needs of all family members.



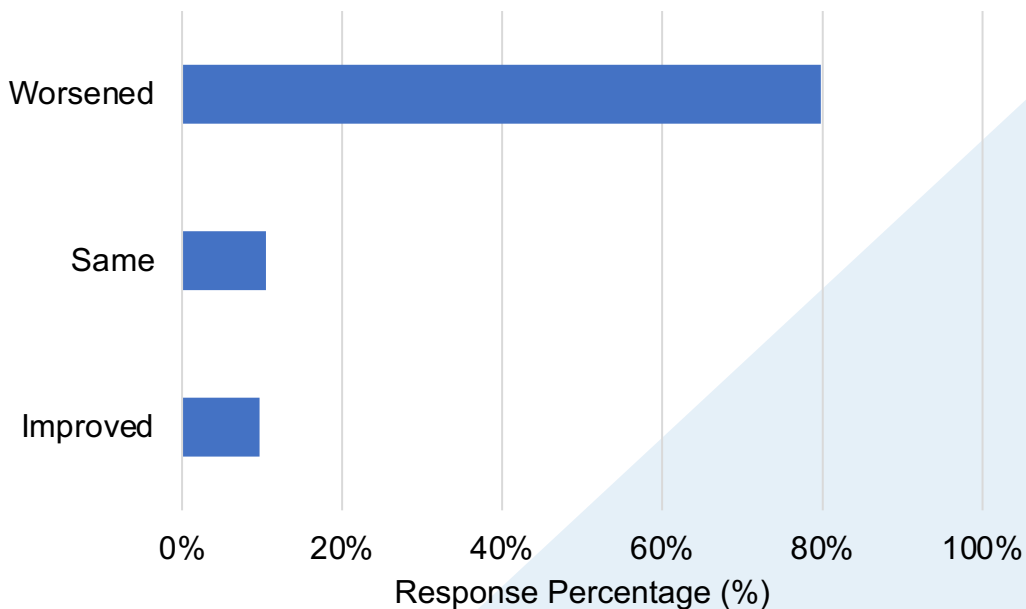
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## 3.5 Emotional Well-Being

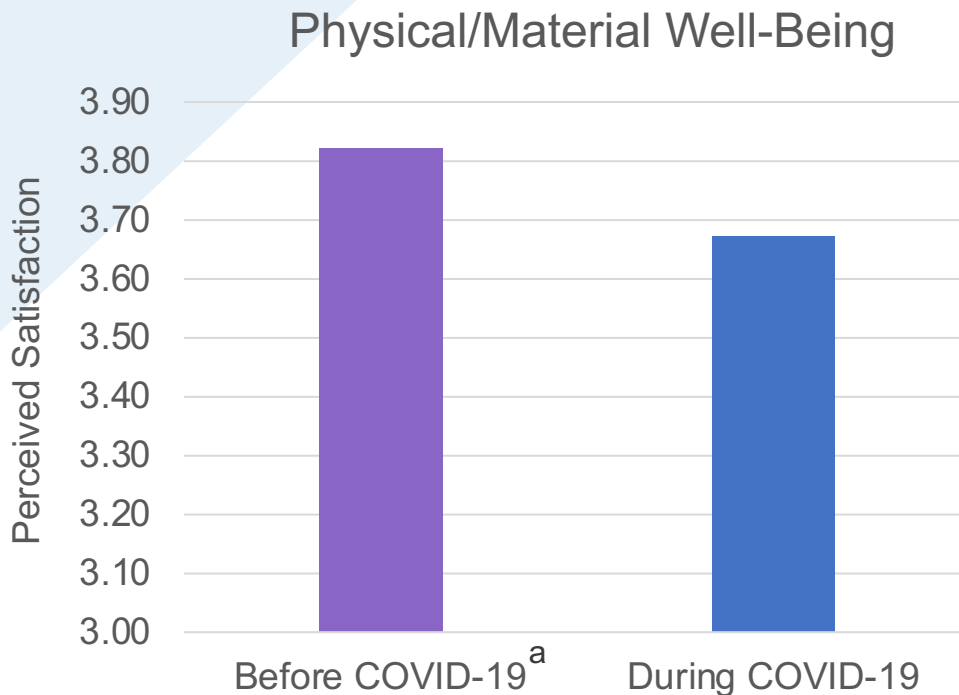
*How has your anxiety levels changed since COVID-19?*



*How has your mood and well-being changed since COVID-19?*



## 3.6 Physical / Material Well-Being



### SCALE ITEMS

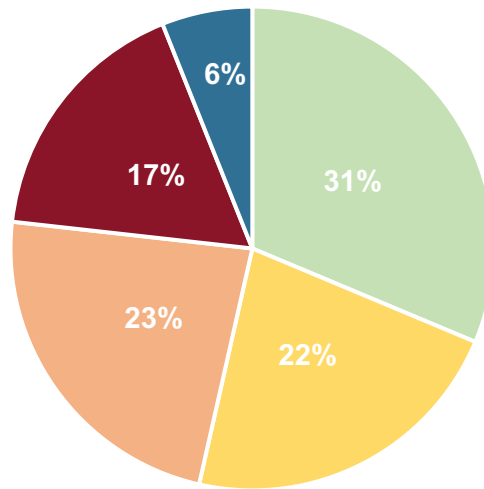
- My family members have transportation to get to the places they need to be.
- My family gets dental care when needed.
- My family gets medical care when needed.
- My family has a way to take care of our expenses.
- My family feels safe at home, work, school, and in our neighborhood.



<sup>a</sup> Data for this sample (Before COVID-19 group) comes from a study by Gardiner & Iarocci (2018). This sample is comparable to the current sample given families were also living in British Columbia with an autistic child under 18 years. However, the groups were not matched on parent education and family income, therefore these comparisons are preliminary and should be interpreted with caution.

## 3.6 Physical / Material Well-Being

*How has COVID-19 impacted your family's income?*



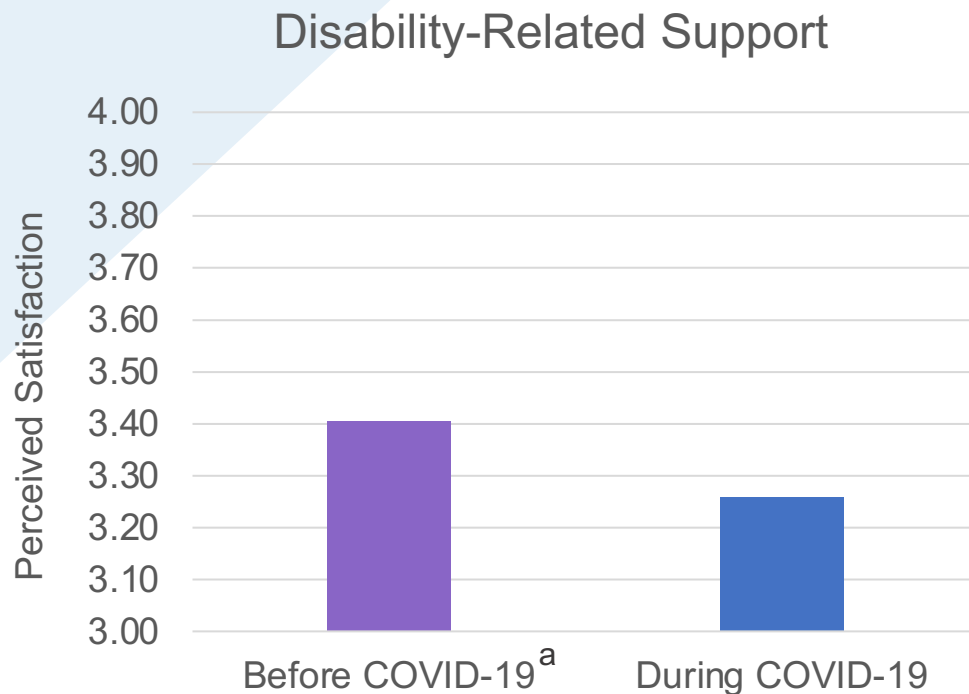
- Not at all
- Slightly (decreased by less than 20%)
- Moderately (decreased by 20-40%)
- Severely (decreased over 40%)
- Other

*"We were spending an additional \$500 per week on food, food delivery costs, and it would have been nice to be able to cover a larger portion of household costs with extra funding."*

*"It is frustrating that half his Autism Funding is going to evaporate unused and we are struggling to pay for things he really needs."*



## 3.7 Disability-Related Support Satisfaction



### SCALE ITEMS

- My family member with special needs has support to make progress at school or workplace.
- My family member with special needs has support to make progress at home.
- My family member with special needs has support to make friends.
- My family has a good relationship with the service providers who work with our family member with a disability.

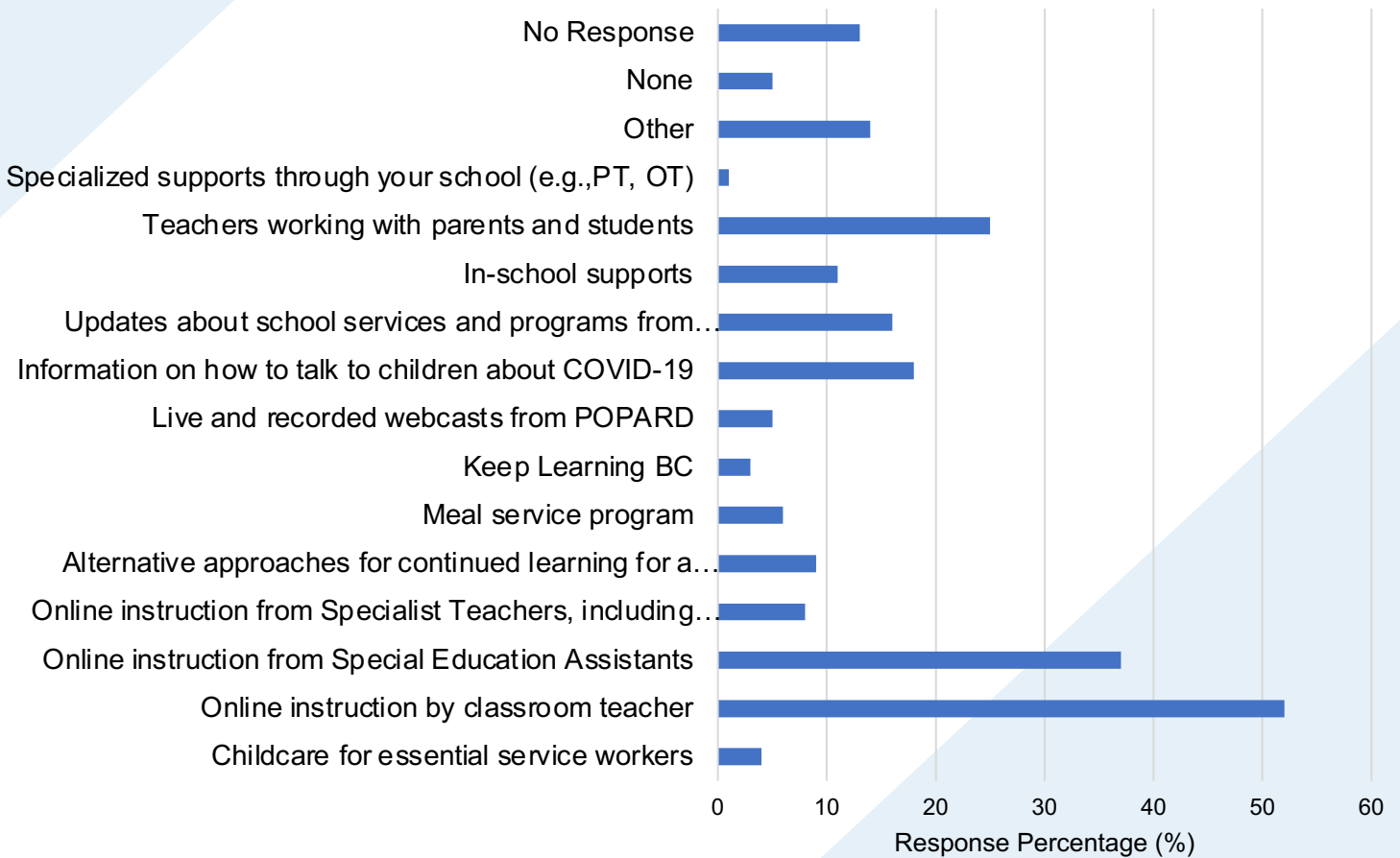


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3.7 Disability-Related Support Satisfaction

MINISTRY OF EDUCATION

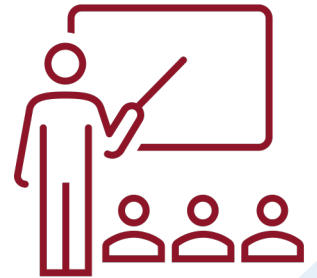
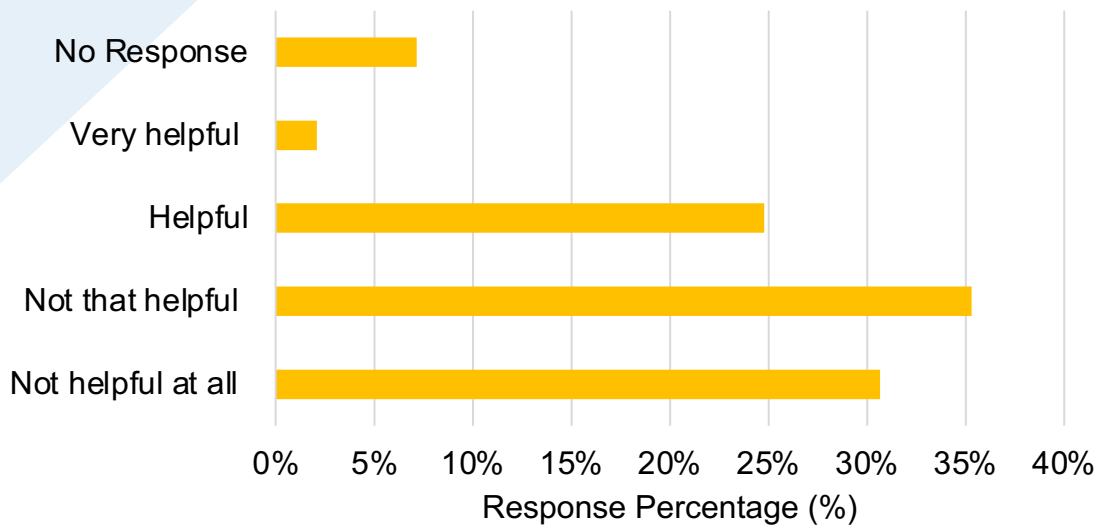
*Which of the following Ministry of Education measures did you access following suspension of in-person classes?*



3.7 Disability-Related Support Satisfaction

MINISTRY OF EDUCATION

*How helpful did you find the Ministry of Education resources that you were able to access?*



*“Information and resources relating to people with disabilities were simply not adequately provided by the Ministry of Education during the pandemic. The ministry has not helped at all.”*

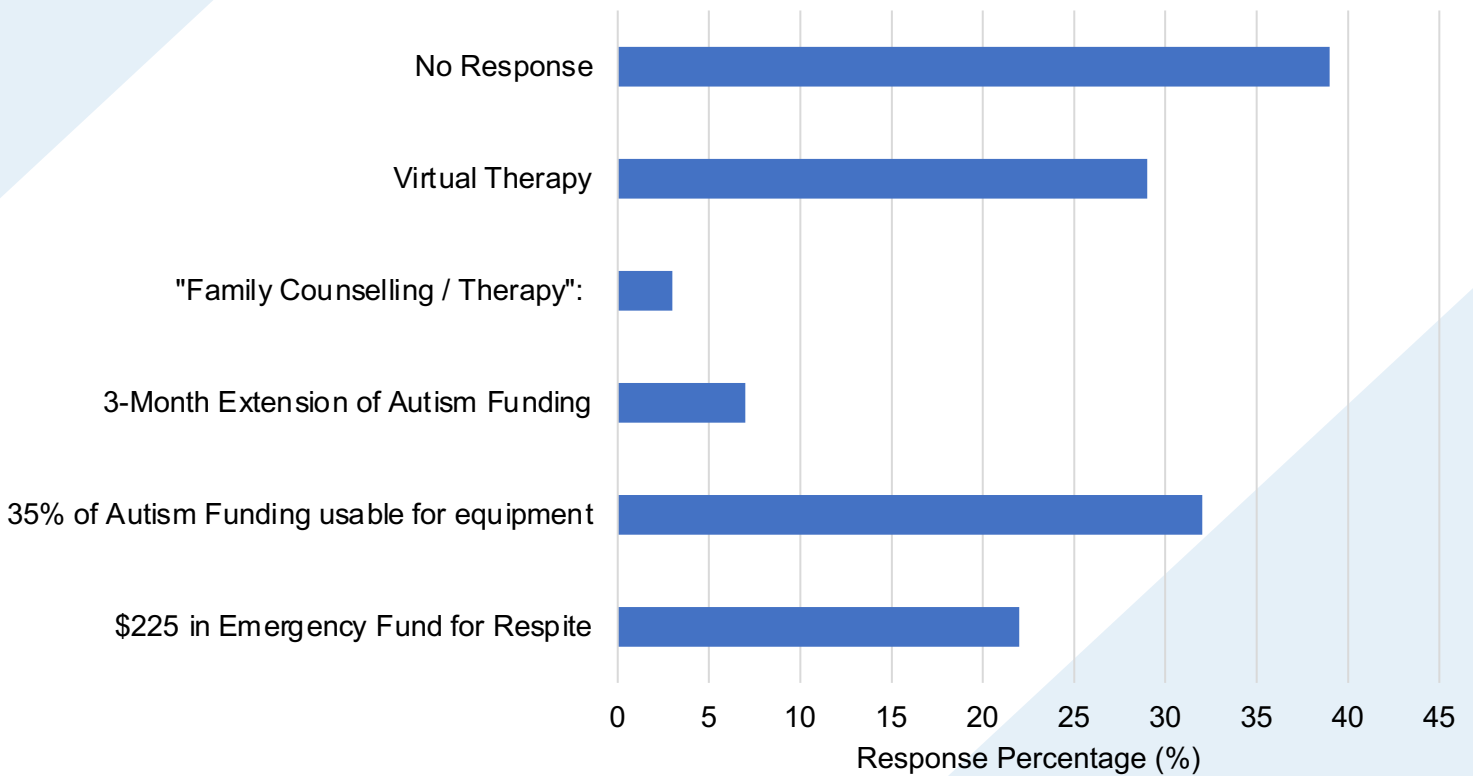




## 3.7 Disability-Related Support Satisfaction

### MINISTRY OF CHILD AND FAMILY DEVELOPMENT

*Which of the following Ministry of Children and Family Development (MCFD) COVID-19 relief measures were you able to access?*

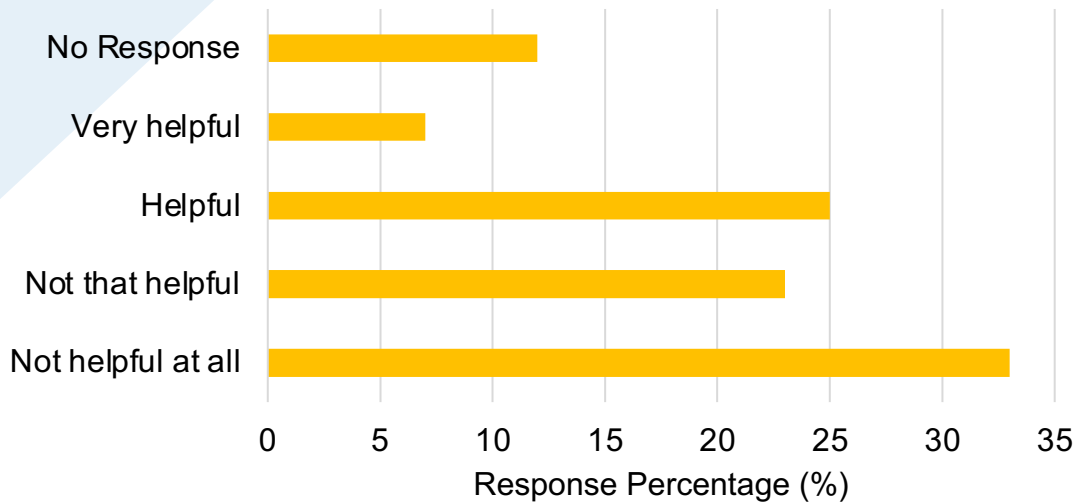


**LESS** than **35%** of families accessed any of these supports

3.7 Disability-Related Support Satisfaction

MINISTRY OF CHILDREN AND FAMILY DEVELOPMENT

*How helpful did you find the MCFD relief(s) you were able to access?*



*“MCFD has been sorely lacking in keeping in contact with families. They are not forthcoming with actual services that could provide help with **caregiver burnout** and dealing with a child with severe **self-injury**.”*



## 4.1

### What did you need that you were missing?

#### FLEXIBILITY IN FUNDING

*“More flexibility with types of physical therapy equipment, helping finding / funding respite, and working with municipalities to open up playgrounds for special needs kids.”*

*“The lack of flexibility from the Autism Funding Unit on extending the funding year is ridiculous.”*

*“We need more flexibility on being able to purchase things that actually help our children. Exercise is one of the top things that helps mental health and yet we can't use any of the funding to pay for exercise equipment or lessons.”*



#### TRANSPARENCY & INFORMATION

*“A complete guide to what was available. All the information was in chunks and I did not get all of them.”*

*“I also didn't know there were other services that were available to me. Honestly, I was just trying to manage the mental and physical health of myself and my family.”*



## 4.1

### What did you need that you were missing?

#### RESPIRE

*“Mainly, the respite grant. I also didn't know there were other services that were available to me.”*



*“We need reliable and safe in-person respite and intervention support.”*

*“The availability of respite care workers is very low in our area. Our ability to access respite care was poor before the COVID-19 pandemic. During the pandemic, it has been more challenging to access respite care.”*

*“I have not found anyone to provide respite for my son. I'm waiting for the paperwork to be processed for respite.”*

# Thank you!

To all who completed the survey, we are grateful for your time and perspectives.

## Contact Us:



[addl@sfu.ca](mailto:addl@sfu.ca)

<http://autismlab.psyc.sfu.ca>