

# The Impact of COVID-19 on Mental Health, Quality of Life, and Service and Support Needs in Families of Children with Autism Spectrum Disorder: Preliminary Findings

Vanessa Fong<sup>1</sup>, Elina Birmingham<sup>1</sup>, Deborah Pugh<sup>2</sup>, & Grace Iarocci<sup>1</sup>

<sup>1</sup>Simon Fraser University

<sup>2</sup>ACT – Autism Community Training

SFU

## BACKGROUND

- In response to the current pandemic, government action has been widely judged to have failed to address the major concerns and needs of families of children with a range of special needs in British Columbia.
- Prior to COVID-19, most caregivers of autistic children had to meet high demands requiring their time and energy.
- It is probable that already existing barriers faced by these families were exacerbated by COVID-19 restrictions, with families isolated and cut-off from most of their support systems.
- Research is urgently needed to examine the impact of COVID-19 on mental health, quality of life and service accessibility to determine the most effective services and supports for families and what essential services must be in place in times of emergency.

## COMMUNITY PARTNERS & COLLABORATORS

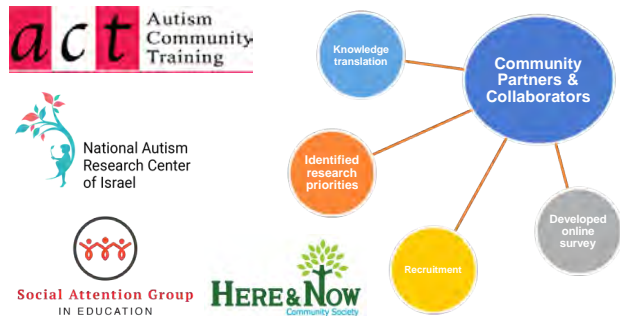


Figure 1. Role of Partner

## OBJECTIVES

- How are families of autistic children living in British Columbia coping during COVID-19?
- What are families' perceptions of the services and supports provided by the Ministry of Children and Family Development (MCFD) and the Ministry of Education?

## METHODS

### PARTICIPANTS

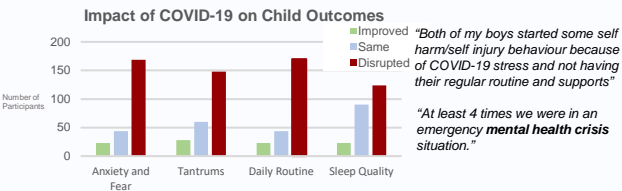
- 238 caregivers living in BC between the ages of 25-64 years (M=42.82; SD=6.65) were included in the present study. Their autistic children were between the ages of 2-21 years (M=10.47; SD=6.65).

### METHODS

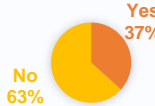
- Online survey assessed functioning and satisfaction with supports during March through June 2020.
- Online survey hosted by Qualtrics from July 30 – September 26, 2020.
- Quantitative data were analyzed using IBM SPSS Statistics version 24.

## RESULTS

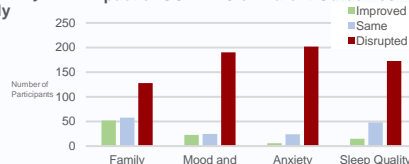
### HOW ARE FAMILIES COPING?



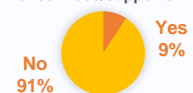
Are you worried your child may physically hurt a family member?



Impact of COVID-19 on Parent Outcomes



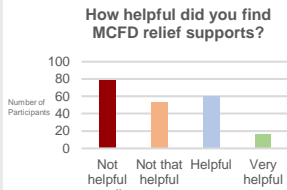
Did you ever consider putting your child into care of MCFD due to lack of services/supports?



“I have been close to relinquishing guardianship to just keep what’s left of my family together.”

## RESULTS CONTINUED

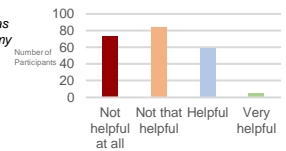
### SERVICES AND SUPPORTS



“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.”

“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**.”

How helpful did you find the Ministry of Education resources?



“Our son simply **fell through the cracks**. Our family has had very little income between March and now due to my **exhaustion** and inability to have energy to work.”

“My child’s mindset of school being for learning and home being for safety and relaxation is a rigid one. He had a **mental health breakdown** about having to do hard work in his safe space. For him, the school year terminated early because he got too **depressed** to function.”

## CONCLUSIONS

- The majority of parents reported that their child’s anxiety, tantrums, daily routine, and sleep quality have worsened during the pandemic.
- The majority of parents reported their family relationships, well-being, anxiety, and sleep quality have worsened during the pandemic.
- Over a third of parents report safety concerns for their family.
- Almost 10% of parents considered putting their child into care.
- The majority of parents report that both MCFD and Ministry of Education supports in response to COVID-19 have been insufficient in meeting their needs.
- Three families reported positive impacts of the pandemic on their child, for example one parent expressed that her son “has sort of thrived with COVID-19...as the day to day social demands have lessened due to quarantine.”
- Open-ended responses indicate the need for mental health supports, respite, and greater flexibility with funding.

## ACKNOWLEDGMENTS

The authors would like to thank all the families who shared their experiences and perspectives. We would also like to thank the Centre for Engagement in Research Initiative (CERI), Mitacs and KBHN for the training and financial support to make this study possible.