



Focus on Research I – April 16, 2021

## **Turning the COVID-19 Crisis into Opportunity: Rethinking family supports to build resilience**

Web Streamed from Vancouver, British Columbia

**Research presented by**  
Professor Grace Iarocci, PhD &  
Vanessa Fong, PhD Candidate  
Simon Fraser University

Moderated by Professor Anthony Bailey, UBC

**Panelists**  
Carey Henry  
Lori Gauthier  
Bo Sang Lee  
Deborah Pugh

*ACT gratefully acknowledges the support of the  
Royal Bank of Canada Foundation for this presentation.*



# Event Schedule

*All times are in Pacific Time*

<b>10:00 – 10:50</b>	Session 1
<b>10:50 – 11:00</b>	Break
<b>11:00 – 12:00</b>	Session 2
<b>12:00 – 12:30</b>	Lunch
<b>12:30 – 1:30</b>	Session 3

## Tips for Improving the Zoom Experience:

- Join the Zoom webinar prior to 10:00am to ensure you can access the platform without issue.
- Be sure your speakers are on or your headphones are plugged in, and the volume is up.
- Check that you have an up-to-date version of Zoom installed: <https://www.zoom.us/download>
- If you are viewing in a web browser,
  - Check that your browser is up to date.
  - If you are having trouble with Internet Explorer or Safari, try [Google Chrome](#).
  - Close all other open ‘tabs’. These use your computer’s memory and slow the connection.



# Acknowledgements

ACT – Autism Community Training thanks our presenters for enabling us to present the first of the two Focus on Research events we are holding this month, to make up for having to cancel last year's presentation because of the pandemic. ACT has held a Focus on Research event annually since 2005, as a way of ensuring that we promote the latest in evidence-based information. However, this is the first one we are presenting via Zoom. We appreciate the flexibility of all of our presenters and our audience as this may require us to innovate as we proceed with our day.

This event has been made possible thanks to the generous support of our individual donors, as well as the Royal Bank of Canada Foundation. We are very grateful to all who enable us to share this important research with families, autistic individuals, community professionals and researchers, around British Columbia, across Canada and internationally.

Those who have attended ACT events over the years know that we depend on community collaboration and support to sustain our work. ACT deeply appreciates the many parents and professionals across British Columbia who volunteer their time and support, donate funds, and help spread the word - especially during these challenging times.

## Free Resources from ACT

**ACT's Coronavirus (COVID-19): Resources for the Autism Community** - ACT has gathered resources specific to those who are neurodiverse, and useful general resources related to COVID-19: [www.actcommunity.ca/covid-19-resources](http://www.actcommunity.ca/covid-19-resources)

**Autism Videos @ ACT (AVA)** – Over 65 quality online videos available free – without a log-in, thanks to our sponsors. [www.actcommunity.ca/videos](http://www.actcommunity.ca/videos)

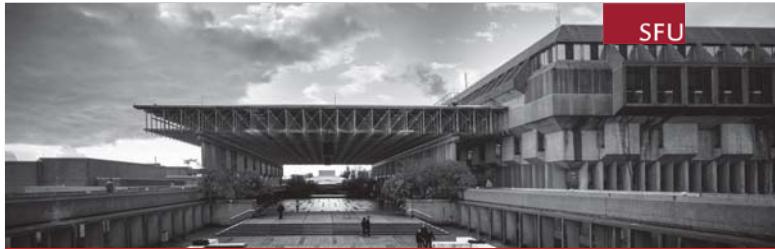
**ACT's Autism Information Database (the AID)** – Like Google for Autism but better! Keyword search nearly 1,400 curated AID records for evidence-informed, practical information resources useful to families and community professionals. [www.actcommunity.ca/aid](http://www.actcommunity.ca/aid)

**ACT's BC Community Resources Database** – Search by your postal code for professionals and service providers throughout BC. [www.actcommunity.ca/aid-search/community](http://www.actcommunity.ca/aid-search/community)

**ACT's Autism Manual for B.C** - 13 chapters! [www.actcommunity.ca/autism-manual-for-bc](http://www.actcommunity.ca/autism-manual-for-bc) -

**ACT's Monthly News Round-Up & Event Alerts** - Sign-up to keep in touch with developments affecting the special needs community. [www.actcommunity.ca/updates](http://www.actcommunity.ca/updates)

**ACT's Facebook** - ACT carefully sources interesting, insightful stories to inform our 8,000 plus followers. [www.facebook.com/autismcommunitytraining](http://www.facebook.com/autismcommunitytraining)



## Turning the COVID-19 Crisis into Opportunity: Rethinking family supports to build resilience

### Acknowledgements

- The authors would like to thank all the parents and caregivers who completed our survey.
- We also acknowledge those who contributed to developing our survey including Dr. Ilan Dinstein, Bo Sang Lee, and Deborah Pugh.
- We would also like to thank Mitacs and the Kids Brain Health Network for the training and financial support to make this study possible.



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## BACKGROUND

### WHY FAMILIES OF AUTISTIC CHILDREN MAY BE UNIQUELY IMPACTED

- Social relatedness and connectedness are at the core of the disability
- Genetic risk means that one or more family members are impacted in some way
- Severity of symptoms does not necessarily reflect the level of need
- We know a great deal about the types of service needs but not how best to meet the needs of families

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### BEFORE THE PANDEMIC

*Quality of Life in Families of Children with Autism Spectrum Disorder: Considerations of Risk and Resilience (Gardiner, 2014)*

- Child characteristics such as adaptive functioning and behavior problems predicts family quality of life

*A Community Engaged Approach to Examining Service Navigation and Quality of Life in Korean Families of Autistic Children (Fong, 2021)*

- System: delays and waitlists for services; ineffective school policies to address child behavioral challenges
- Provider/Professional: lack of qualified professionals; negative attitudes; lack of guidance navigating services
- Family/Cultural: language and communication difficulties; out-of-pocket costs; stigma impeded service access

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## STUDY CONTEXT

## STUDY CONTEXT

- Prior to the pandemic, families of autistic children experience high levels of stress and strain due to behavioural and learning challenges their children face
- COVID-19 has exacerbated challenges due to school closures, parental employment changes, social isolation, and a loss of essential services and supports

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## WHAT IS COMMUNITY ENGAGED RESEARCH?

“Partners contribute expertise and share decision making and ownership to increase knowledge and understanding of a phenomenon, and integrate that knowledge with interventions, policy advocacy, and social change to improve quality of life for communities and reduce health inequities.”

Coombe et al., 2020 p. 553



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## COMMUNITY ENGAGEMENT

### Role of Community Partners

- Identified research priorities
- Formulated the research questions and objectives
- Co-created COVID-19 online survey
- Recruitment
- Knowledge translation



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## RESEARCH QUESTIONS

1. What is the impact of COVID-19 on the child, caregiver, and family?
2. How does FQOL differ before and during COVID-19 lockdown?
3. What are families’ service and support needs?
4. What characteristics of the family are linked to improved FQOL?

## METHODS

## STUDY SAMPLE

Characteristics	During COVID-19 (N=238)
*Respondent relationship to child (% mothers)	89.7%
Mean age of caregiver (years, SD)	42.82 (6.65)
Range	25 - 64
Mean age of child (years, SD)	10.47 (3.77)
Range	1 - 20
Gender of child (n, % male)	82 (78.4%)
*Median household income	\$80,000 - \$109,999
*Ethnicity (% non-White)	16.7%

\*126 caregivers completed these demographic questions

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## MEASURES

- Data collected from July 30 – September 26, 2020
- Online survey assessed child, caregiver, family functioning and quality of life during March through June 2020
- Beach Family Quality of Life Scale

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# FINDINGS: IMPACT ON THE CHILD AND CAREGIVER

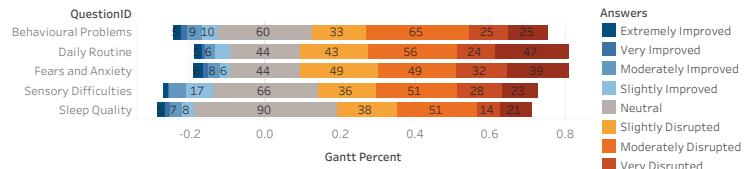
## RESEARCH QUESTIONS

1. What is the impact of COVID-19 on the child, caregiver, and family?
2. How does FQOL differ before and during COVID-19 lockdown?
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4. What characteristics of the family are linked to improved FQOL?

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## COVID-19 IMPACT ON CHILD

### COVID-19 Impact on Child

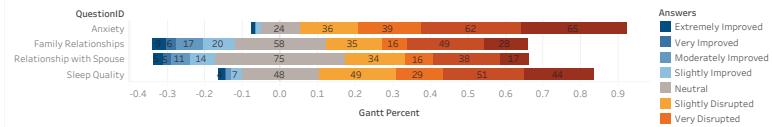


Gantt Percent for each QuestionID. Color shows details about Answers. Size shows Percent of Total Sizing. The marks are labeled by count of Tableau data. The view is filtered on Answers, which excludes Null.

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## COVID-19 IMPACT ON CAREGIVER

### COVID-19 Impact on Caregiver



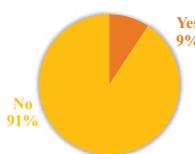
Gantt Percent for each QuestionID. Color shows details about Answers. Size shows Percent of Total Sizing. The marks are labeled by count of Tableau data. The view is filtered on Answers, which excludes Null.

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## COVID-19 IMPACT ON CAREGIVERS

### Did you ever consider putting your child into care?

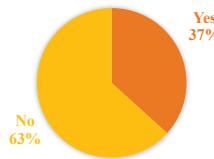
"I have been close to relinquishing guardianship to just keep what's left of my family together."



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## COVID-19 IMPACT ON CAREGIVERS

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



*"I am considering entering into a special needs care agreement or relinquishing partial custody so I can manage the safety issues that have arisen during lockdown."*

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## RELATIONSHIP BETWEEN CHILD AND CAREGIVER ANXIETY

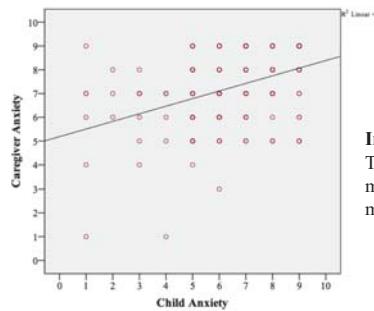
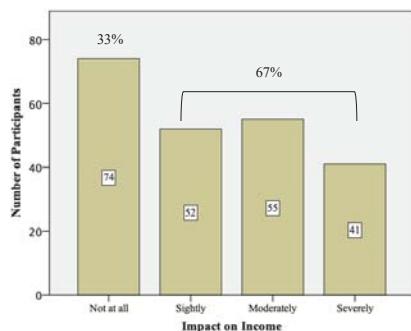


Figure 1. Overall correlation child and caregiver anxiety ( $r = .396, p < .001$ )

**Implications:**  
Targeting caregiver anxiety may help improve child mental health outcomes

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## COVID-19 IMPACT ON THE FAMILY



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## SUMMARY

- During the pandemic, families report negative outcomes during the lockdown period
- There is a relationship between child and caregiver anxiety
- 9% of caregivers have considered putting their child into care
- 37% of caregivers were worried their child would physically hurt another family member
- 67% of families report a slight to severe impact on their family income

# FINDINGS: IMPACT ON THE FAMILY

## WHY FOCUS ON THE FAMILY?

- Developmental disability is unexpected, atypical
- No parenting role models or prior knowledge on how to parent a child with DD
- Family functions as a system and impact is felt on the whole unit
- Child is more dependent on family and for longer
- Family *relies* on government, professional services-they are essential

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## RESEARCH QUESTIONS

- What is the impact of COVID-19 on the child, caregiver, and family?
- How does FQOL differ before and during COVID-19 lockdown?**
- What characteristics of the family are linked to improved FQOL?
- What are families' service and support needs?

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## STUDY SAMPLE

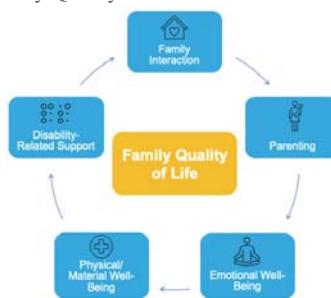
Characteristics	Before COVID-19 (N=174)	During COVID-19 (N=238)
Respondent relationship to child (% mothers)	83.9%	89.7%*
Mean age of caregiver (years, SD)	45.32 (7.64)	42.82 (6.65)
Range	27 - 64	25 - 64
Mean age of child (years, SD)	11.93 (5.85)	10.47 (3.77)
Range	2 - 36	1 - 20
Gender of child (n, % male)	148 (85.1%)	82 (78.4%)
Median household income	\$80,000 - \$109,999	\$80,000 - \$109,999*
Ethnicity (% non-White)	19.0%	16.7%*

\*126 caregivers completed these demographic questions

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## FAMILY QUALITY OF LIFE

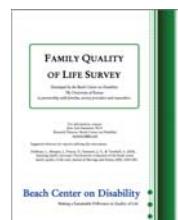
→ Beach Center Family Quality of Life Scale



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## BEACH CENTRE FOOL SCALE

- 25 items over 5 domains
  - Satisfaction
- Quantitative (self-report)
  - 'Very Dissatisfied' (1) to 'Very Satisfied' (5)
- Approx. 20 minutes
- Psychometrically valid
  - (Hoffman et al., 2006; Summers et al., 2005;
  - Wang et al., 2006)



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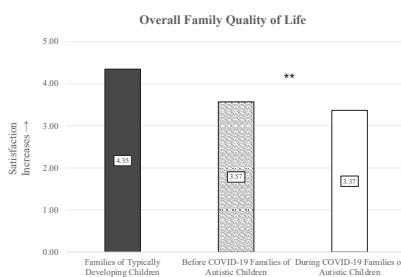
## EXAMPLE ITEMS FROM THE BEACH FOOL SCALE

How satisfied am I that...	Very Dissatisfied	Dissatisfied	Neither	Satisfied	Very Satisfied
1. My family enjoys spending time together.	<input type="checkbox"/>				
2. My family members help the children learn to be independent.	<input type="checkbox"/>				
3. My family has the support we need to relieve stress.	<input type="checkbox"/>				
4. My family members have friends or others who provide support.	<input type="checkbox"/>				
5. My family members help the children with schoolwork and activities.	<input type="checkbox"/>				



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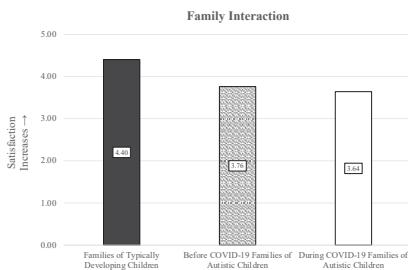
## FAMILY QUALITY OF LIFE



Data for families of TD children comes from Zuna, Selig, and Summers (2009)

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## FAMILY QUALITY OF LIFE DOMAINS

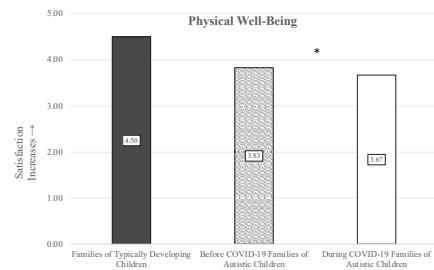


*"Right now my child stays and visits with any relative that will agree to have her just to provide a healthier environment for her siblings and myself as our relationships are eroding without additional supports and marginal access to respite."*

Data for families of TD children comes from Zuna, Selig, and Summers (2009)

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## FAMILY QUALITY OF LIFE DOMAINS

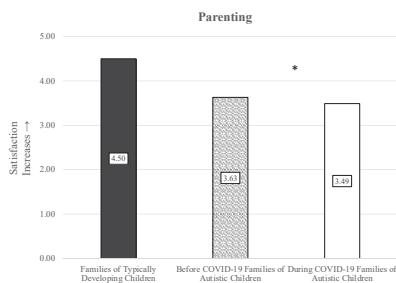


*"The increased living costs during the pandemic have caused some hardship (ex. purchasing extra cleaning supplies, soap, masks, gloves, hand sanitizer)."*

Data for families of TD children comes from Zuna, Selig, and Summers (2009)

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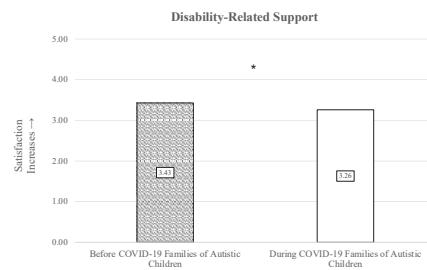
## FAMILY QUALITY OF LIFE DOMAINS



*"We have had anxiety and stress for years but COVID made everything worse. As the caregiver, I wasn't doing a good job and felt like it was all my fault. Not being able to give my child a proper structure has caused major tantrums and destructive behaviours at home. Not being able to go anywhere."*

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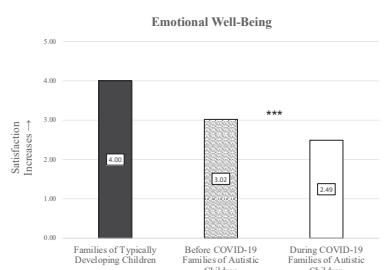
## FAMILY QUALITY OF LIFE DOMAINS



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

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## FAMILY QUALITY OF LIFE DOMAINS



*"At least four times we were in an emergency mental health crisis situation."*

Data for families of TD children comes from Zuna, Selig, and Summers (2009)

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## SUMMARY

- Families during the pandemic report a significantly lower overall FQOL
- Out of all 5 domains, caregivers report the lowest satisfaction in the emotional well-being domain

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# QUESTIONS

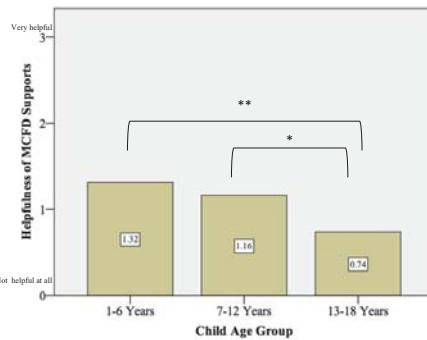
# FINDINGS: SERVICE AND SUPPORT NEEDS

## RESEARCH QUESTIONS

1. What is the impact of COVID-19 on the child, caregiver, and family?
2. How does FQOL differ before and during COVID-19 lockdown?
3. **What are families' service and support needs?**
4. What characteristics of the family are linked to improved FQOL?

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## SATISFACTION WITH MCFD SUPPORTS



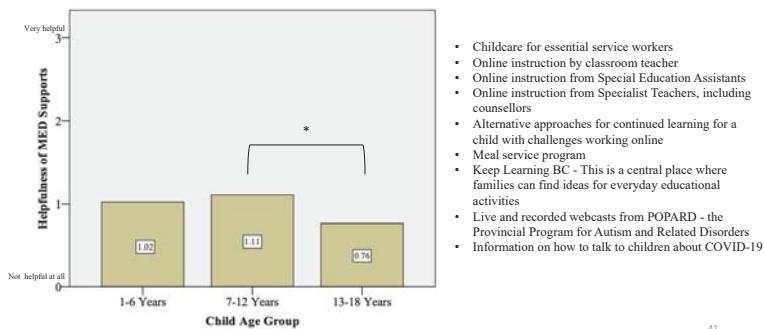
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## WHAT GOVERNMENT SUPPORTS DID YOU NEED?

Code	Frequency	Quotes
Access to Respite	46	"We had to lean on every resource we had with family and friends to give ourselves a break from our son, since he is very needy and requires constant supervision. Since we were denied respite through an application for disabilities, we thought we had no options for respite. This would have made a huge difference for us."
Centralized Information	44	"It would be helpful to have information with links to applications, clear outlines for who qualifies, and simple processes to obtain access to resources and supports."
Flexibility in Funding	29	"I was very upset I wasn't able to access [equipment]. It would have made a huge difference in my child's and my whole families' life by helping him. I'm very disappointed in that whole process."
Emergency / Safety Support (e.g., aggression)	13	"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."

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## SATISFACTION WITH MED SUPPORTS



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## WHAT EDUCATIONAL SUPPORTS DID YOU NEED?

Code	Frequency	Quotes
Educational Assistant / Academic Support	38	"The daily check-ins with his EA were essential for him to stay connected to school."
In-Person Learning Support	38	"My son needs hands on therapy and learning with someone in person. Virtual learning is absolutely impossible for my son due to his disability."
Individualized Instruction Consistent with IEP	26	"His IEP was not taken into consideration when making his educational plan during COVID-19."
Funding for Educational Supplies and Equipment	17	"The programs the school ran needed an Apple device for many reading projects. I tried to access the funding but they would not approve this purchase because it was only if you had not purchased equipment in the past 3 years. I could not understand why I could not claim the additional 20% to support my daughter for online learning."

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## WHAT TYPES OF INFORMATION DID YOU NEED?

Code	Frequency	Quotes
Parent Support Groups	14	"A way to connect with other parents of children with autism. I feel like I'm struggling alone."
Mental Health Resources	13	"A Kids Mental Health app or line for just helping kids with questions or anxieties but that aren't necessarily an emergency. They have something for adults, so why not kids."
Social Groups / Social Activities	13	"Online social groups for kids with similar interests (Minecraft, Pokémon, transit)."

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## SUMMARY

- Caregivers of 13-18 year old's report the lowest satisfaction with government and educational supports
- Parents prioritize government supports such as respite, centralized information, flexibility in funding, and emergency/safety supports
- For their child's education, parents prioritize supports from EAs for virtual learning, in-person learning options, individualized instruction consistent with IEPs, and funding for educational supplies and equipment
- Caregivers prioritize information related to parent support groups, mental health resources and supports, and social groups/activities for their child

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## FINDINGS: CHARACTERISTICS LINKED TO IMPROVED FQOL

## RESEARCH QUESTIONS

1. What is the impact of COVID-19 on the child, caregiver, and family?
2. How does FQOL differ before and during COVID-19 lockdown?
3. What are families' service and support needs?
4. **What characteristics of the family are linked to improved FQOL?**

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## WHAT IS RESILIENCE?

"Characteristics, dimensions, and properties which help families to be resistant to disruption in the face of change and adaptive in the face of crisis situations."

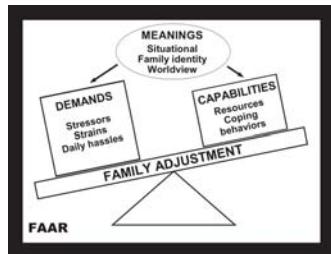
-McCubbin & McCubbin,  
1988, p. 247



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## RESILIENCE

- Ability to develop optimally despite exposure to elevated risk or adversity
- Strengths-based perspective
- Family is considered a dynamic system
- Risk and protective factors
- Interaction between child, family, community, and environmental factors



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## CHILD CHARACTERISTICS

- Fewer behavioral problems
- Fewer mental health concerns
- "My child is a calm, happy, easy-going person, who is very articulate and grounded and emotionally stable. She's handled this all really well. Better than her parents, in some ways."
- Connections to peers
- "We're really doing just fine. Our kid is happy, calm, and socializing with her friends online."

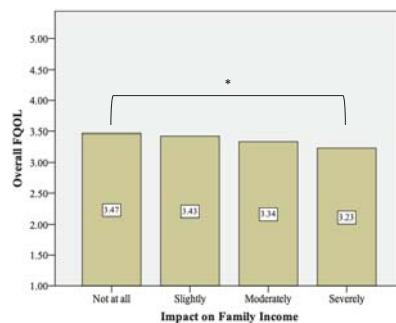
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## FAMILY CHARACTERISTICS

- Parent training and expertise
  - "I feel that we have been very fortunate in terms of my career and training. His mom is very hard working and good at organizing and working with him."
- Parent resourcefulness
  - "We had to lean on every resource we had with family and friends to give ourselves a break from our son, since he is very needy and requires constant supervision."
- Extended family and friends
  - "Without the support of family, parents, aunts, and sisters we would have had way worse outcomes with our children."
- Stable income, two-parent households

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## FAMILY INCOME AND FOOL



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## GOVERNMENT SUPPORT CHARACTERISTICS

- Flexibility in funding
  - "I was very grateful to be able to use 35% of funding and sign the forms as a parent. We know what our kids need. Using a professional that is unfamiliar with the child just causes more anxiety and often costs hundreds of dollars."
- Availability of respite
  - "We were fortunate to still receive respite funding during this time and that was greatly helpful to us."
- Funding for equipment and educational supplies
  - "Being able to get equipment for my son without having to get a signature from a professional was extremely helpful as I usually do not have access to a service provider that can do so. Also, the increased flexibility of use for the directly funded respite was helpful as I could not use the funding within its usual requirements."

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## SCHOOL SUPPORT CHARACTERISTICS

- Consistent communication with teachers and school staff
  - "Teachers checked in and provided weekly lesson plans which I was able to build upon to ensure my child was learning at a similar pace as before."
- Availability of EAs to support learning
  - "The daily check-ins with his EA were essential for him to stay connected to school."
- Connecting families with educational supports
  - "Our school is very supportive. As soon as I contacted the Special Needs Resource Coordinator, she did what she could to involve my child with the school resources."

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## MENTAL HEALTH SUPPORTS

- Availability of mental health supports
  - "I encouraged my son to have counselling to help him balance his hormones and mitigate depression/anxiety."
- Prioritized mental health and well-being
  - "We did reach out to mental health services as we are not trained to support our son in the ways he might need. Reaching out before there is any sign of trouble is what we think is best."
- Individual and family counselling
  - "Appointments with his psychologist and family counsellor have helped him with these concerns. Again, those supports have been critical for us."

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## CAREGIVER MENTAL HEALTH AND FQOL

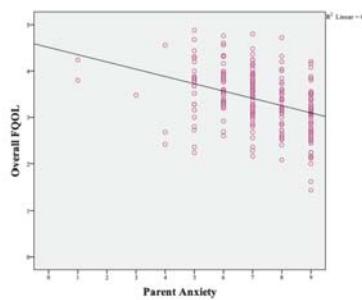


Figure 2. Overall correlation between FQOL and caregiver anxiety ( $r = -.377$ ,  $p < .001$ )

Parent Anxiety

Family Quality of Life

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## CAREGIVER MENTAL HEALTH AND FQOL

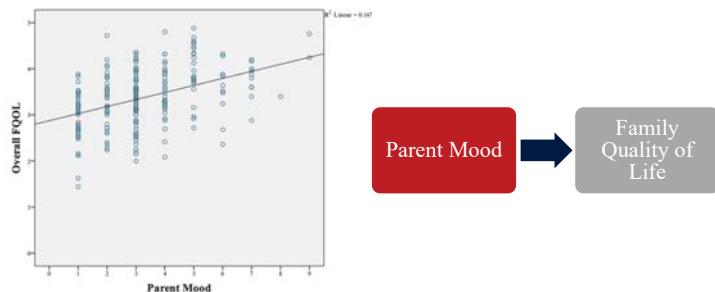


Figure 1. Overall correlation between FQOL and caregiver mood ( $r = .410$ ,  $p < .001$ )

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Parent Mood

Family Quality of Life

## TAKEAWAY MESSAGES

## RECOMMENDATIONS

- Fong & Iarocci (2020)
  - Improve access to parent and child mental health services
  - Policies are needed that emphasize flexibility for the diversity of childcare needs
    - Easy and quick access to government relief funding to prevent financial burden and help ease the transition back to work.
    - Childcare support programs that allow parents to better cope with their responsibilities during the pandemic.
  - Governments should protect and support civil society organizations and communities who play a critical role in implementing policies, protecting public health, and providing access to needed supplies, medical care, and social services.

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## KNOWLEDGE TRANSLATION

## KNOWLEDGE TRANSLATION

- Conferences
- Policy Report
- SFU Panel: *Addressing the Impact of the Pandemic on Families of Children with Special Needs*

### VANCOUVER SUN

*'It's not just a matter of throwing money at this,' says Autism Community Training's executive director. 'We need a change in the whole attitude towards children with special needs and their families in the province'*



## THANK YOU!



## REPORT

UNDERSTANDING THE  
IMPACT OF COVID-19 ON  
FAMILIES OF AUTISTIC  
CHILDREN IN BRITISH  
COLUMBIA  
REPORT – DECEMBER 2020



### Feedback or Questions?

**Website:** <http://autismmlab.psyc.sfu.ca>  
**Email:** [addl@sfsu.ca](mailto:addl@sfsu.ca), [vcfong@sfsu.ca](mailto:vcfong@sfsu.ca)  
**Facebook:** <https://www.facebook.com/SFUaddl/>

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## QUESTIONS