

About Presenter

Name: Kirsten Penrose

Pronoun: She/her

Physical appearance: Tall, light skin, blue eyes, long blond/brown wavy hair

Location: Windsor, Ontario

Contact information: penrose1@uwindsor.ca

- Contact information can be used to obtain a PDF copy of presentation slides

Reminder that audience can use their space as needed





COVID-19 Pandemic: Parents Find Innovative Ways to Connect with Their Children Who Reside In Supportive Residential Living Environments

Kirsten Penrose, Micheline Senia, Chad A. Sutherland, and Sean Horton

APEX Research Group, Department of Kinesiology,
University of Windsor



University of Windsor

© Penrose et al.

Accessible Language Choices

Supported Residential Living:

- Any adult with an intellectual disability not living in their family home
- Needs 24-hour support to live independently in the community

Supported Independent Living:

- People who live on their own or with roommates of their choosing
- Adults with an intellectual disability that require minimal and individualized support
- Needs based and can be provided on a daily, weekly or monthly basis



Accessible Language Choices

Persons living with autism and an intellectual disability

- Used by local support agency

Adult child

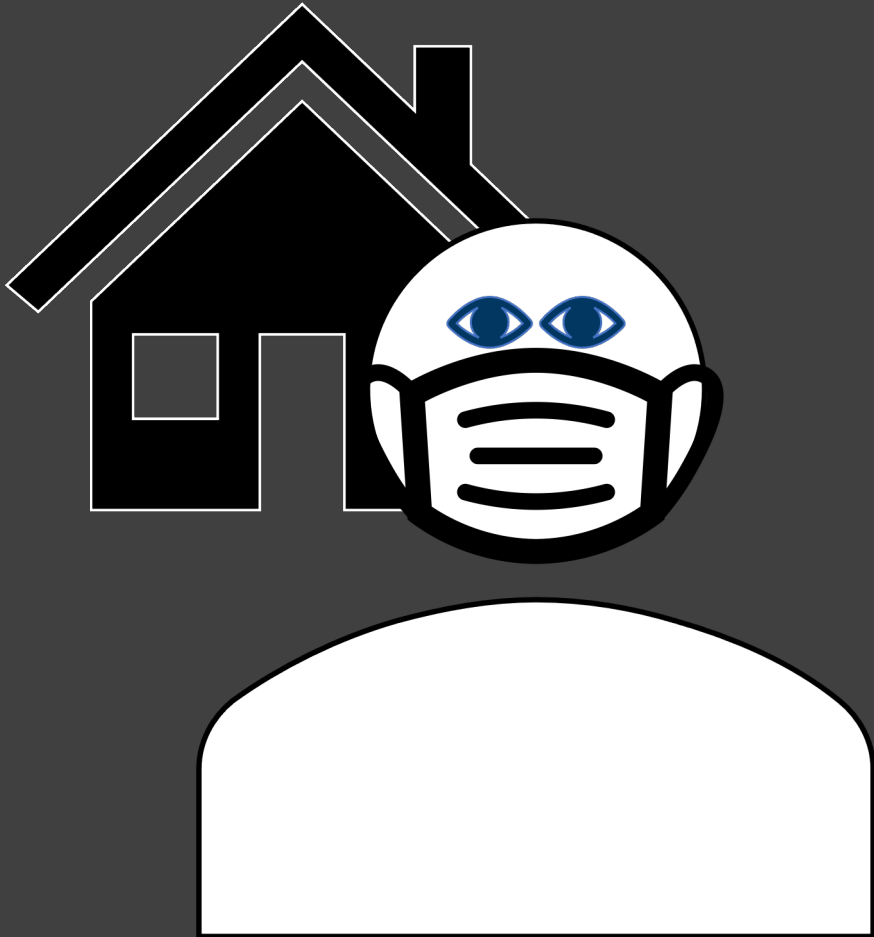
- Child of participant, but who has reached the age of majority



COVID-19 Restrictions



COVID-19 Impact on Adult Child



Anxiety¹

Challenging Behaviours¹

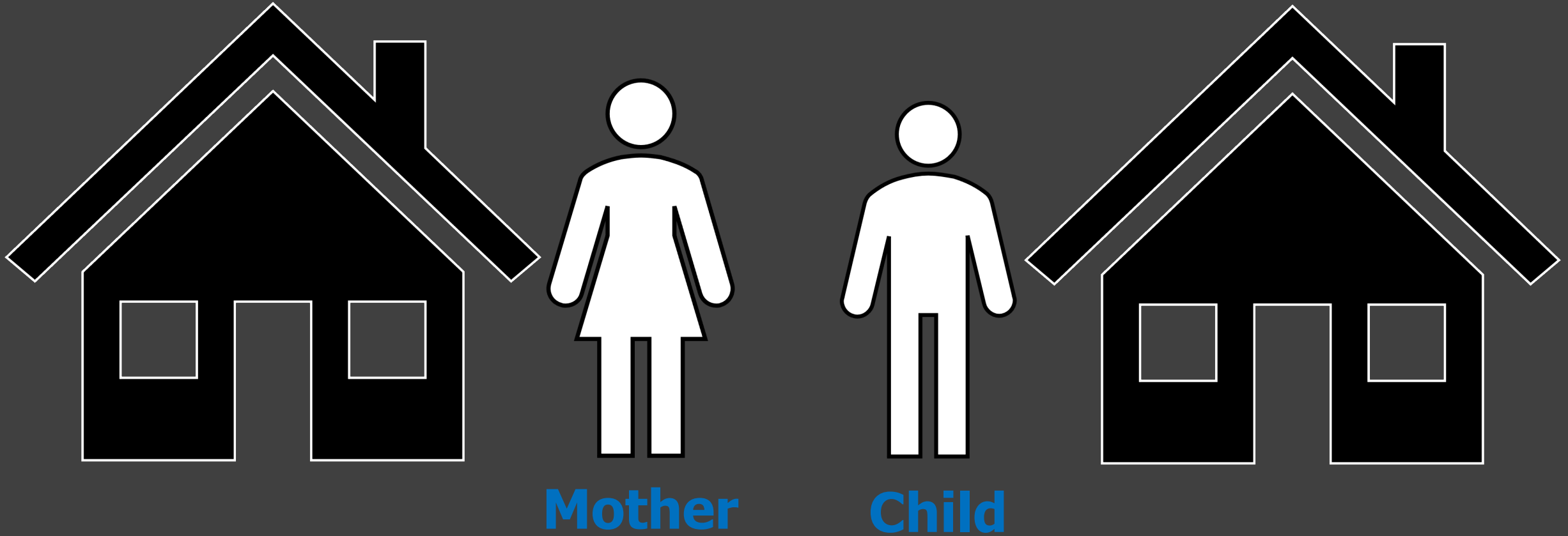
¹ Colizzi, M. et al., Sironi, E., Antonini, F., Ciceri, M. L., Bovo, C., & Zoccante, L. (2020). *Brain Sci.*, 10(6), 341.



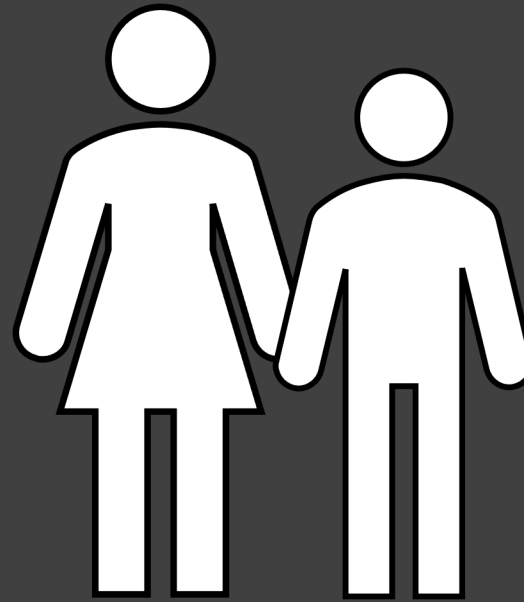
COVID-19 Impacts Adult Child's Access to Resources



Unique Challenges for Mothers



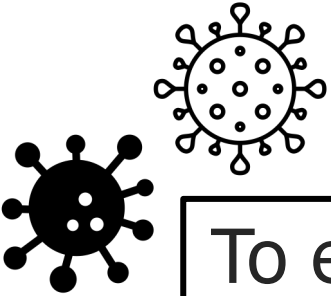
Acknowledging Parents As Essential Caregivers



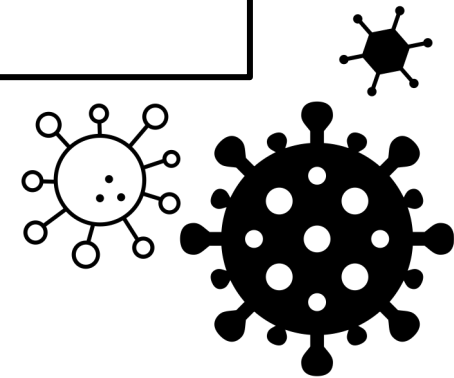
Mother & Child



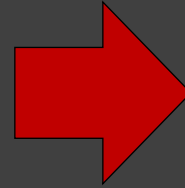
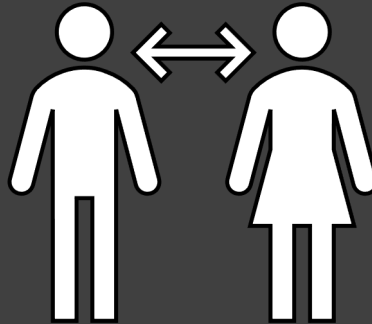
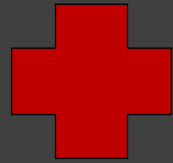
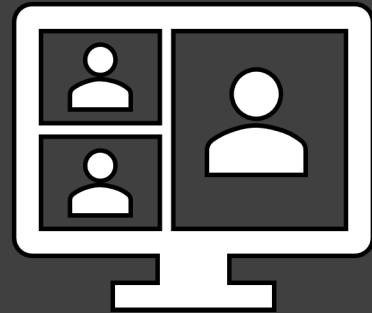
Purpose of the Study



To explore the everyday experience of parenting an adult child with autism and an intellectual disability who **resided in supported residential living environments** during the COVID-19 pandemic.



Parental Concerns & COVID-19 Effects



Anxiety²

² Brown, I. (2020, May 9). *The Globe and Mail*.



COVID-19 Restrictions Unauthorizing Visits



Examining the Lived Experience Will...



Help community organizations provide services and information most needed and impactful



Inform policy makers towards the preparation of contingency plans



Reduce stress and anxiety for all involved



Methodology

Theoretical Approach

Social constructionist epistemology

- In-depth interviews
 - Disability understood within social world that creates its meaning ⁶
 - Meaning and knowledge acquired through interaction and exploration of one's own reality ⁷
- Strengths-based approach **INSTEAD OF** traditional deficits-based approach – 'burden' ⁸

⁶ Oliver. (1992). *Disabil Soc*, 7(2), 101-114.

⁷ Crotty. (1998). *The foundations of social research: Meaning and perspective in the research process*. London, UK: Sage.

⁸ Tint, & Weiss. (2016). *Autism*, 20(3), 262-275.



Participants

Findings drawn from a set of 2 interviews

- Completed after onset of pandemic

Purposive sampling ⁹

- **10 mothers of adult children (21 years of age or older) with autism and an intellectual disability, residing in supported residential living environments**
- **Mothers show greater levels of negative affect ¹⁰**

¹¹ Patton, M. Q. (2002). *Qualitative evaluation and research methods*. Newbury Park, CA: SAGE Publications.

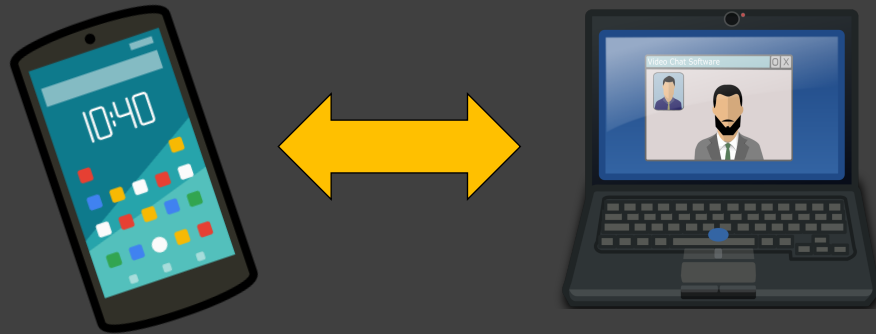
¹² Smith, Hong, Seltzer, Greenberg, Almedia, & Bishop. (2010). *J Autism Dev Disord*, 40(2), 167-178.



Data Collection Procedure

One-on-one semi-structured interviews

- (avg. 47 minutes; May – December 2020)
- Develop trust and rapport



- Participants provided informed consent
- Questions addressed two specific areas

These Photos by Unknown Author are licensed under CC BY-ND & CC BY-SA



University of Windsor

© Penrose et al.

Data Analysis

Inductive thematic analysis ¹¹

- Bring clarity to shared meanings and experiences
- Familiarization with the data, and extraction of codes
- Organization of coded data into candidate themes
- Definition and clarification of finalized themes

Findings:



¹¹ Braun, V., Clarke, V., & Weate, P. (2016). In Routledge Handbook of Qualitative Research in Sport and Exercise. Routledge.



Results

N = 10 mothers ($M_{\text{age}} = 60.3$ years)

- **8 male ($M_{\text{age}} = 30.6$ years) & 2 female children ($M_{\text{age}} = 34.5$ years)**



Results

N = 10 mothers ($M_{age} = 60.3$ years)

- **8 male ($M_{age} = 30.6$ years) & 2 female children ($M_{age} = 34.5$ years)**

Incomes ranged:

\$10,000 - > \$150,000



Results

N = 10 mothers ($M_{age} = 60.3$ years)

- 8 male ($M_{age} = 30.6$ years) & 2 female children ($M_{age} = 34.5$ years)**

All children resided in supported living environments	Incomes ranged: \$10,000 - > \$150,000
7 - Married/common-law w/ father of child 1 - Married/common-law (not bio parent of child) 2 - Single	4 - Caucasian 1 - English/French 1 - Irish/French 1 - Lebanese 1 - Nigerian 1 - Serbian/Caucasian 1 - Did not disclose ethnicity



Results

N = 10 mothers ($M_{age} = 60.3$ years)

- 8 male ($M_{age} = 30.6$ years) & 2 female children ($M_{age} = 34.5$ years)**

All children resided in supported living environments	Incomes ranged: \$10,000 - > \$150,000
7 - Married/common-law w/ father of child 1 - Married/common-law (not bio parent of child) 2 - Single	3 - Caucasian 1 - English/French 1 - Irish/French 1 - Lebanese 1 - Nigerian 1 - Serbian/Caucasian 1 - Did not disclose ethnicity
8 - Post-secondary education 2 - High-school education	Interviews were completed in Southwestern Ontario



Emerging Themes

Three themes:

1

Visitation Restrictions

2

Challenges to Communication

3

Need for Appropriate Emergency Services



Visitation Restrictions

“Yeah. It broke my heart not to be able to touch him or to hug him. It made us step back in terms of progress. He took it as us not trusting him, physically, and being afraid of him. So even developmentally, like in some of the things that we worked on, it's affected him that way as well.”

“We've had to implement where we do like a driveway visit. So, he stays in his garage, we stay in our car, and we talk to each other with the cell phone. [...] Because he's having suicidal thoughts, like I'm saying he really tanked. So, he tanked and then had probably the worst week ever, and then we started the two drive-bys a day.”



Challenges to Communication

“They were trying to get me to do video visits, but because our visits are so structured and routine, I was afraid that she wouldn't understand why I wasn't there. And that she would get upset and maybe self-abusive. And, you know, the only thing worse than not seeing her, is seeing her hit herself.”

“We're recording messages and sending it like video messages but not like a back-and-forth thing because I think they're worried that he might get upset, and [...] it's very present when you're video chatting with somebody. [...] I made a little story for him too, [a] stay-at-home social story”



Need for Appropriate Emergency Services

“[At a psychiatric ICU during the pandemic] My son slept and ate on a concrete floor. He refused to use their bed there. But he was locked in because he has autism. Even though his behaviors were very [good]... But people were constantly coming in his room. So that was his life for five months. It was inhumane. [...] We had to advocate for the smallest things”

“A lot of the communication that we have had with [local support agency] has been fantastic. The managers and the staff, there are extremely supportive and caring individuals that have tried really, really hard to support us in any way that they could during this pandemic, and help us feel connected with our son even though we weren't able to touch him. They were listening to us. They were really listening and trying. Whereas at the hospital, it was very different.”



Discussion

- **Level of skills + resources + state of mental health = unique experience of challenges**
- **Communication is essential, but can take on many forms**
- **Failing to plan is planning not to succeed**



Limitations

- **Size of sample = lack of diversity**
- **Majority of sample from same support agency**
- **Data were collected at various points during the pandemic**



Future Directions

Where should we look next?

- Fathers and secondary caregivers
- Divorced/single parents
- Targeted parent groups (e.g., age, occupation, SES)
- Minority groups



Conclusion

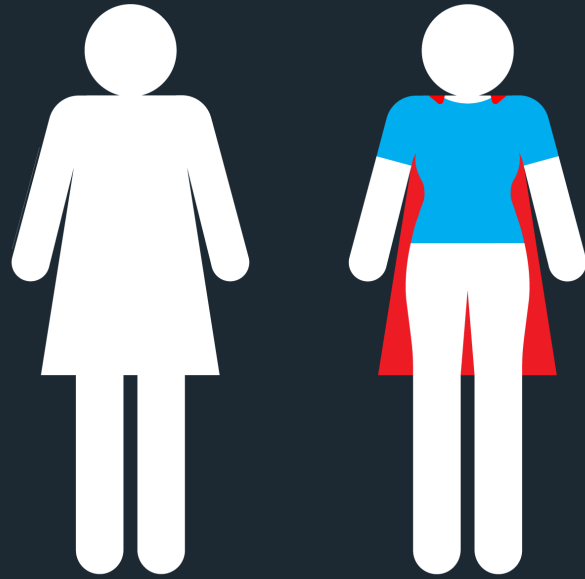
Children who resided in a supportive residential living environment

Children who resided with their mothers

Different challenges

All mothers demonstrate resilience, creativity, and perseverance





It was never a dress.

(em)powered by  axosoft

This Photo by Unknown Author is licensed under CC BY-NC



University of Windsor

© Penrose et al.

Thank You!



University of Windsor

© Penrose et al.

References

- ¹ Colizzi, M., Sironi, E., Antonini, F., Ciceri, M. L., Bovo, C., & Zoccante, L. (2020). Psychosocial and behavioural impact of COVID-19 in autism spectrum disorder: An online parent survey. *Brain Sciences*, *10*(6), 341. <https://doi.org/10.3390/brainsci10060341>
- ² Brown, I. (2020, May 9). Two metres and a world apart: Life in lockdown for me and my disabled son. *The Globe and Mail*.
- ³ Seucharan, C. (2020, September). Some people with disabilities have been isolated in their care homes for months. Experts say it could lead to an 'avalanche' of mental-health issues. *The Globe and Mail*. <https://www.theglobeandmail.com/canada/article-some-people-with-disabilities-have-been-isolated-in-their-care-homes/>
- ⁴ Ameis, S. H., Lai, M. C., Mulsant, B. H., & Szatmari, P. (2020). Coping, fostering resilience, and driving care innovations for autistic people and their families during the COVID-19 pandemic and beyond. *Molecular Autism*, *11*(61). <https://doi.org/10.1186/s13229-020-00365-y>
- ⁵ Milberger, S., Marsack-Topolewski, C., Janks, E., & Samuel, P. S. (2020). Family Caregiving During the COVID-19 Pandemic. *Developmental Disabilities Network Journal*, *1*(2), 91-101.
- ⁶ Oliver. (1992). *Disabil Soc*, *7*(2), 101-114.
- ⁷ Crotty. (1998). *The foundations of social research: Meaning and perspective in the research process*. London, UK: Sage.
- ⁸ Tint, & Weiss. (2016). *Autism*, *20*(3), 262-275.
- ⁹ Patton, M. Q. (2002). *Qualitative evaluation and research methods*. Newbury Park, CA: SAGE Publications.
- ¹⁰ Smith, Hong, Seltzer, Greenberg, Almedia, & Bishop. (2010). *J Autism Dev Disord*, *40*(2), 167-178.
- ¹¹ Braun, V., Clarke, V., & Weate, P. (2016). Using thematic analysis in sport and exercise research. In *Routledge Handbook of Qualitative Research in Sport and Exercise* (pp. 191-205). Routledge.

