ABSTRACT SUBMISSION FORM

LET'S TALK ABOUT



Exploring the role of sex and gender on health research





CHRD 2020: Abstract Submission Form

Submitter Name

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Title

A qualitative exploration of the impact of Covid-19 on families of children with neurodevelopmental disorders

Background

Children with neurodevelopmental disorders (NDD) often require extensive support services to help build social resilience and provide parents with respite from associated demands. Many such services have been affected by the COVID-19 pandemic, thereby placing additional strain on families.

Objective

We aimed to describe parental perceptions on how these restrictions have affected family well-being and the ability to access services for children with NDDs.

Methods

A purposive sample of Manitoban parents with a child with a parent-reported NDD diagnosis (N=7), recruited subsequent to participation in the online Parenting During the Pandemic study, completed virtual qualitative interviews. Reported diagnoses included attention deficit hyperactivity disorder, autism spectrum disorder, speech and language disorder, Down's syndrome and sensory processing disorder. Transcribed interviews were analyzed using thematic analysis. Transcripts were read for surface content, then re-read for latent meaning. Codes were created and applied systematically across the transcripts, and themes were subsequently identified. Rigour was enhanced through use of multiple coders.

Results

A total of 3 themes were identified in the qualitative interviews. The first theme, , pre-pandemic educational format caused anxiety for children with NDDs, captured the social struggles that these children faced prior to the pandemic as well as a reluctance to return to school. In the second theme, competing priorities, parents described having "a lot more on [their] plate and no break", partially attributed to a loss in support services for their children with NDDs. The last theme, a lack of options, detailed that these parents were

not given adequate information or tools to support their children's specialized needs.

Conclusion

Parents perceive that restricted access to services for children with NDDs during the time of COVID-19 negatively impact familial mental health. Further research is necessary to determine the best support methods and interventions to prevent long-term detriment caused by the pandemic.

Theme:

Community Health / Policy

Do you have a table/figure to upload?

Yes

Untitled

Qualitative themes.pdf

Are you willing to participate in Goodbear's Den?

Yes

Presenter Status:

Undergraduate Students

What was your role in the project?

Design

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Themes	Interview Quotes	
1. Pre-Pandemic Childcare/Educational Format Caused Anxiety for NDD Child	"My son, I felt like thrived through this whole thing because I think at school he struggled with social connection. He had friends, but it was also difficult for him to maintain those friendships, because sometimes his behaviour would upset his peers" – Participant 6	
	"He does not particularly like socializing with other kids. He would rather play by himself. He thinks this is the biggest treat in the world not having to go." "He says, I am not going back to the classroom" – Participant 1	
2. Competing Priorities		
a. Struggle to maintain life balance	"It has been a bit hectic, because as you know everybody was at home and with having a special needs child this is more demanding" – Participant 5	
	"Yes, it is stressful for sure. Yes, just a lot more on my plate and no break." – Participant 1	
b. Access to services related to NDD have been negatively affected by pandemic lockdown	"My biggest concern is that my son will, as a result of the pandemic, that he will lose out on the time that has been lost. These services officially end when a child enters kindergarten and so my son will be entering kindergarten in the fall of 2020. It is quite sad that we waited like two years for help." – Participant 4	
	"Absolutely, like I definitely would have gone back to places or like to have had her seen someone, she just regressed so bad, but you just feel like there really was not any option" – Participant 7	
c. Negative social/emotional impact on siblings related to NDD child	"I feel sad for my other son because he is not getting the kind of attention that he deserves because we have to focus on the child with special needs" – Participant 4	
	"Her behavior was kind of getting worse, would have violent outbursts again. Often, they happened, and my husband is gone, and she physically attacks me, so I have to kind of make sure that my other kids are in a safe spot and then I put a barrier between herself and me" – Participant 7	
d. Increased opportunity for family bonding	"There was some additional family bonding that happened that does not normally take place because were all out at different activities in the evenings" – Participant 3	
	"I think the biggest thing I would say regarding positive changes is he has more time with us as a family" – Participant 5	
3. A Lack of Options		
a. Poor dissemination of information to parents	"There were no messages to me saying you know [child] has no work posted, what is going on, that kind of thing" – Participant 2	
	"We never received a letter or email saying that they were cancelled or postponed, but as I said, you know if we had not reached out, I am not sure we would have received any services for his speech during COVID" — Participant 3	
 b. Virtual format does not work for delivery of specialized services and educational materials 	"The virtual platform does not work because that is not how we interact on a day to day basis through a screen, it is very unnatural" – Participant 4	
	"The socialization piece I think is probably one of the biggest learning goals for a 3-year-old, so I do not think that is being met at this point" — Participant 1	

c. Increased wait-times for support services	"He was on the waitlist for respite", "This was supposed to start but then because of the pandemic, it was delayed" – Participant 5	
	"The parent support worker I believe was postponed, we are still on the waitlist, but we probably would have gotten in already if it had not been for the pandemic" – Participant 7	
d. An uncertain future	"[Early learning ASD program] has been postponed indefinitely, so I cannot say when that will resume, if at all." – Participant 4 "He said we can't go outside because of the virus" – Participant 2	