

"They Say 'We Don't Have Resources! We Don't Have EAs [educational assistants]! We Can't Handle Your Kids!': Mothers' Perspectives on Their Autistic Children's School Experiences

*Ils disent : "Nous n'avons pas de ressources ! Nous n'avons pas d'AE [aide-enseignante]!
 Nous ne pouvons pas nous occuper de vos enfants ! Le point de vue des mères sur les
 expériences scolaires de leurs enfants autistes*

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Abstract

In 2018, one in 66 children in Canada received a diagnosis of autism spectrum disorder. Among the various psychosocial needs related to this diagnosis, a prevalent need is related to adapted services available within schools. For full participation in school, autistic children may need additional supports and individualized education plans; however, these may not always be available. We conducted semi-structured interviews with 11 mothers who are raising autistic children in Ontario. We drew on interpretive phenomenological analysis to explore their narratives of their experiences of navigating educational systems for their children. Two main themes emerged from this analysis: (1) experiences related to systemic issues, and (2) experiences related to the effects of systemic issues on children and mothers. From the second theme, the following sub-themes emerged: (a) the unrealistic expectations placed on autistic children at school, (b) the lack of resources to support autistic children, and (c) the actions and attitudes of school staff toward autistic students. Mothers' narratives revealed the often-negative effects of the lack of specialized approaches, knowledge and understanding within the school system. To ensure they receive quality

education adapted to their needs, autistic children and their mothers need support as they navigate the school system. Recommendations are offered for better adapted support for families.

Résumé

En 2018, un enfant sur 66 au Canada a reçu un diagnostic de trouble du spectre autistique. Parmi les divers besoins psychosociaux liés à ce diagnostic, un besoin prévalent est lié aux services adaptés disponibles dans les écoles. Pour participer pleinement à l'école, les enfants autistes peuvent avoir besoin de soutiens supplémentaires et de plans d'éducation individualisés, mais ceux-ci ne sont pas toujours disponibles. Nous avons mené des entretiens semi-structurés avec 11 mères des enfants autistes en Ontario. Nous nous sommes appuyés sur l'analyse phénoménologique interprétative pour explorer leurs récits d'expériences des systèmes éducatifs pour leurs enfants. Deux thèmes principaux ont émergé de cette analyse : (1) les expériences liées à des problèmes systémiques plus larges (c.-à-d. les besoins non satisfaits) et (2) les expériences liées aux effets des problèmes systémiques sur les enfants et les mères (c.-à-d. les attentes irréalistes, le manque de ressources de soutien et les actions et attitudes du personnel scolaire à l'égard des élèves autistes). Les récits des mères ont révélé les effets souvent négatifs du manque d'approches spécialisées, de connaissances et de compréhension au sein du système scolaire. Pour s'assurer qu'ils reçoivent une éducation de qualité, adaptée à leurs besoins, les enfants autistes et leurs mères ont besoin d'être soutenus lorsqu'ils naviguent dans le système scolaire. Des recommandations sont proposées pour un soutien mieux adapté aux familles.

Mots-clés : troubles du spectre de l'autisme, école, recherche qualitative, mères, enfants

Introduction

In 2018, one in 66 Canadian children aged 5 to 17 years was diagnosed with autism spectrum disorder¹ (Public Health Agency of Canada, 2018), which is characterized by core sensory features (i.e., over- and under-sensitivity and/or highly focused interests) or other perceptual and self-regulation differences (Samson et al., 2014; Weiss et al., 2014). Autism is diagnosed at different life stages, most often in early childhood, particularly around the transition stage of school entry (Government of Canada, 2018). The extent to which autism is expressed is vast and individual: no two autistic children are the same. Despite the many challenges that autistic people encounter, they have many strengths, including attention to detail, early reading abilities, logical thinking, heightened memory, and more (Altogether Autism, 2022). The inclusion of autistic people hinges upon individual and societal attitudes, in which oppressive and stigmatizing systems are rooted:

Numerous studies have suggested school environments may contribute to stigma and stress for autistic children and add to challenges for autistic children and their caregivers (Brewer, 2018; Brown et al. 2021; Cappadocia et al., 2012; Danker et al., 2016; DePape & Lindsay, 2016; Hodge et al., 2019). Many of these issues have been rooted in societal pressures of normalcy, and thus educators (and autistic students themselves) work to fit individuals into societal norms rather than holding space for autistic students to be present as they are in the school environment (Hodge et al., 2019). School-related concerns for autistic students have included lack of

¹ Authors use identity first language because it is preferred by autistic people (e.g., Bury et al., 2020).

education assistance and/or one-on-one attention in the classroom, educator knowledge of autism, and support and understanding of autism demonstrated by school boards (Brown et al. 2021). Further research has shown autistic students are often subjected to bullying (Cappadocia et al., 2012; Danker et al., 2016); unnecessary expulsions (Brewer, 2018) and suspensions (Starr and Foy, 2012); feelings of stress, anxiety, and frustration due to the inflexible, chaotic, and unpredictable nature of the school environment; and fear of academic failure (Danker et al., 2016).

The review by DePape and Lindsay (2016) revealed that parents of autistic children felt stigmatized and blamed by the school system for their children's diagnosis. Further, parents felt their children were unsupported because teachers lacked understanding of autism and how to support their needs (DePape & Lindsay, 2016). Similar experiences were echoed in an interview that was published in this journal (Journal on Developmental Disabilities) in which the author remained anonymous (Anonymous, 2010). In this interview, a mother of an autistic child who was also a schoolteacher and researcher, described a time in which her son was physically restrained by an administrator and referred to as "*evil*" (p. 71). This mother also noted parents of autistic children felt blamed and judged by the school system, which can be incredibly "*traumatizing*" (Anonymous, 2010, p. 72).

While research has identified the general challenges for autistic children within the school system, there has been limited research examining how these experiences affect mothers at an in-depth level, which can inform solution-based strategies to mitigate such challenges. As such, this study aimed to understand the lived experiences of mothers raising autistic children, detailing their school experiences specifically. Authors have chosen to focus strictly on mothers because they are socially and historically the primary care providers to children and have unique experiences (Pakaluk & Price, 2020; Ridgeway & Correll, 2004; Ryan & Runswick-Cole, 2008).

Methods

This study utilized a qualitative approach – specifically, phenomenology – which involves "*carefully and thoroughly capturing and describing how people experience a phenomenon – how they perceive it, feel about it, judge it, remember it, make sense of it, and talk about it with others*" (Moustakas, 1994, p.104).

Recruitment

After receiving ethics approval from the affiliated university (REB #4716), mothers of autistic children were recruited via flyers distributed by local organizations supporting families raising children with disabilities. Recruiting only mothers contributed to sample homogeneity. Mothers of autistic children known to the researchers were also invited to take part in the study and participants were encouraged to invite other mothers they knew who may have been interested. To be eligible for the study, mothers had to reside in Ontario, be proficient in English, and have an autistic school-aged child. All authors hold expertise in qualitative methods and interest in the experiences of family members of people with disabilities; however, the authors were not caregivers of autistic children.

Data Collection

Prior to the interviews, mothers signed a consent form and completed a background questionnaire, which included questions about age, education, marital status, and information about her autistic child (age, gender, age at diagnosis, comorbid conditions). One-on-one semi-structured interviews were conducted in-person with each participant about the diagnostic process, effects on daily life, resource accessibility (for the child and the family), concerns for the future, and advice for other parents. Interviews were audio recorded, transcribed verbatim, and supplemented with field notes documented before, during, and after the interview (e.g., time, place, location, emotional responses). Completed transcripts were emailed to participants allowing participants to ensure the transcript was accurate. This also gave them the opportunity to delete, change, or elaborate on any of the content (Lincoln & Guba, 1985) information and answer any follow-up questions from the researchers. For confidentiality, pseudonyms were used, and all identifying information was removed from transcripts.

Data Analysis

Transcripts were analyzed using interpretive phenomenological analysis (IPA) as described by Smith and Osborn (2007) first by each author individually, then together as a group. The first three authors conducted three to four interviews each, transcribed their own audio recordings, and listened to the other six to seven interviews to become immersed in the data. All authors read each transcript multiple times for comprehension, then looked for “what is interesting or significant” (Smith & Osborn, 2007, p. 67) about their experiences. These steps were all taken independently, and then the authors met to discuss their initial findings. Through discussion together, the authors brainstormed how the concepts could be organized into subthemes, and the subthemes into themes. The first author generated a list of themes and subthemes from this discussion. The other authors reviewed this list with respect to the original transcripts and their personal notes. This process was repeated multiple times until all authors agreed on the final themes and subthemes (presented below).

Results

Eleven biological mothers participated, ranging in age from 29 to 51 years (average = 38.5 years). Their children were mostly male ($n = 7$, 63.6%) and between the ages 6 and 18 years (average = 11.6 years) (see Tables 1 and 2). Interview length ranged from 36 to 111 minutes (average = 67 minutes). While mothers were not explicitly asked about the school system, all discussed it as significant to their experiences raising autistic children. Two themes emerged: (1) systemic issues, and (2) systemic effects (see Table 3 and 4). Susanne – one of the mothers – poignantly summarized the group’s experiences:

*“They [the school] say ‘we don’t have resources, we don’t have EAs, we can’t handle your kids.’ ... **it is the families [emphatic]** that end up having to do everything for these kids in terms of schooling.”*

Table 1*Demographic Information of Mothers*

Pseudonym	Level of Education	Marital Status	Employed
Carolyn	'Some university'	Married	No
Deb	High school	Married	Yes: Full time
Justine	College	Married	Yes: Full time
Nancy	College	Married	No
Vicky	High school	Common law	Yes: Full time
Bailey	College	Separated	Yes: Part time
Cara	College	Single	Yes: Full time
Wendy	University	Married	Yes: Full time
Hannah	College	Married	Yes: Full time
Brenda	University	Married	Yes: Full time
Susanne	Master's Degree	Married	Yes: Part time

Table 2*Demographic Information on Children*

Parent Pseudonym and (Child Pseudonym)	Sex of Child	Age of Child at Time of Study (years)	Age of Child at Diagnosis
Carolyn (Lisa)	Female	18	16
Justine (Nathan)	Male	10	9
Deb (Dane)	Male	9	5
Nancy (Emily)	Female	6	4
Vicky (Andrew)	Male	14	6
Bailey (Tyson)	Male	6	6
Cara (Zoe)	Female	16	8
Wendy (Jack)	Male	10	6
Hannah (Timmy)	Male	16	6
Brenda (Steve)	Male	17	3
Susanne (Michael)	Male	6	3

Systemic Issues

Mothers described concerns arising from their experiences; specifically, challenges stemming from structural components of the Ontario school system. These challenges have been summarized in three subthemes (see Tables 3 and 4).

Table 3*A List of Themes and Subthemes that Emerged from the Data*

Theme	Subthemes
Systemic Issues	<ol style="list-style-type: none"> 1. Unrealistic Expectations: "His needs are not being met in the classroom" 2. Lack of...*: "He's not a priority" 3. School Staff: "It comes down to one person"
Systemic Effects	<ol style="list-style-type: none"> 1. Effects on Children: "He was really struggling" 2. Effects on Mothers: "It's overwhelming"

* Lack of funding, resources, support, etc. at school. See pg. 6 for a description of this subtheme.

Unrealistic Expectations: “His needs are not being met in the classroom”

There was incongruency between school support systems and the abilities of autistic children, in that instructions were delivered in a way that was not accessible for autistic children, and therefore limited their opportunities to learn meaningfully and effectively. Vickie described her son's experience: *“They're saying six instructions and he's still trying to figure out number one.”* In other cases, teachers underestimated the academic abilities of children and did not see their potential in the classroom. For example, Deb hired a private tutor to help her son who “struggled” with math but found his ability was much higher than indicated by his schoolteacher:

“The private tutor was able to get him to do grade 6 math. He's in grade 3 and supposedly at a grade 2 level. So clearly his needs are not being met in the classroom to help succeed.”

Rather than using an individualized approach to instruction, teachers were using a one-size-fits-all approach, which did not account for autistic children's unique abilities. Mothers listed transitions between activities, excess classroom stimuli, numerous rules, verbal instruction, and keeping up with peers interfered with their children's ability to learn.

Lack Of...: “He's not a priority”

Mothers expressed frustration with the limited resources available to their children at school. An example was provided by Wendy, who stated: *“Jack's school has, I think, 750 students and they have one resource teacher.”* Communication was also lacking between school staff and mothers, as Hannah stated: *“I have emailed the guidance counsellor in the past, nothing back. Like, no communication between us.”* Mothers felt their children could succeed at school if they were provided adequate supports; however, they listed lack of resources, understanding, and flexibility as barriers to reaching their children's educational goals. That said, they also recognized day-to-day issues at school were the results of larger concerns, such as limited provincial funding and overwhelming demands placed on teachers.

School Staff: “It comes down to one person”

Mothers reported school staff could *“make or break”* (Deb) a child's experience at school. In most cases, mothers shared the challenges that they and their children experienced with teachers, principals, vice principals, and school counsellors. Mothers described school staff as *“awful”* (Brenda) and *“horrendous”* (Hannah). However, some mothers shared stories of their children thriving because of school staff. For instance, Wendy described her son's teacher as *“phenomenal... she believed in him whole heartedly and what he could do and what he was capable of.”* Carolyn conveyed that, if it were not for the school counsellor, her daughter's diagnosis of autism would have been mistaken for social anxiety. While positive experiences were briefly mentioned by a few mothers, they were uncommon and outweighed by negative experiences.

Systemic Effects

The systemic issues had far reaching consequences, not only on children, but also mothers. The subtheme *Effects on Children* describes some of the effects mothers attributed in their children to shortcomings in the school system. Likewise, the subtheme *Effects on Mothers* describes the ways mothers were personally affected by the school system, both directly and indirectly (e.g., via their children).

Effects on Children: “He was really struggling”

Mothers described the potential effects school had on their children, saying anxiety had “*sky-rocketed*” (Vickie) because of school. For instance, Deb said her son’s anxiety level went from “*25% to 95%*.” Additional effects on children included them “*feeling stupid*” (Vickie), having sleeping troubles, being bullied, and experiencing social struggles. Cara described the social struggles her daughter experienced, saying: “*She would sit there by herself, aware that she was different... she's alone. With her toys and her brushes and people making fun of her.*” These struggles increased over time, with mothers explaining the complexities associated with being autistic at school seemed to heighten each year, especially as peers noticed differences and autistic children fell further behind academically (see Table 4).

Effects on Mothers: “It’s overwhelming”

While children were affected by the school system, mothers described significant effects on their own lives as well, such as the need to be a “*squeaky wheel*” (Cara) and constantly advocate for their children’s needs. This vigilance was associated with stress, high emotion, and out-of-pocket expenses (e.g., paying for assessments, hiring private tutors). While there were instances where advocacy was effective, mothers felt defeated or out of control. Cara recalled when her daughter was bullied, saying “*I couldn’t do anything for her. And you know the teachers, they’re not going to do shit for you.*” This lack of control was a source of sadness for mothers: “*What breaks my heart is that, I think that Jack’s out there in the school world for example, lost, scared, confused, sad. And I can’t control that*” (Wendy). Advocating for their children was described as a second job due to the amount of time and effort involved.

Table 4

Exemplar Quotes within each Subtheme

Subtheme	Exemplar Quote
<p>Unrealistic Expectations: “...his needs are not being met in the classroom” (Deb)</p>	<p>“<i>Since he has started with the public board it has been a struggle, the whole thing has been a struggle. Because...he is not ready to be in a classroom with twenty kids and one teacher. It is too much for him, there is too much stimuli[stimulation] and there is too much going on and he can’t concentrate on what the teacher is doing.</i>” – Susanne</p>

	<p><i>“I don't put a ceiling on her, but I'm aware of limitations. There's a difference, I'm going to push her, I'm going to push her like hell because that's my job as a mom. But I'm also aware that you know, we all have our limits.” – Cara</i></p> <p><i>“They're saying six instructions and he's still trying to figure out number one. So there's that. And, plus all the other noises in the classroom, very distracting.” – Vickie</i></p> <p><i>“And I mean we've always encouraged him to engage learning and love learning and it's you know. But for that to happen, his needs need to be met where he's at. And it becomes more and more uh, again rigid of, in my experience so far this year, of a system because they're dealing with a lot more. The expectations for learning are a lot higher.” – Wendy</i></p> <p><i>“...we proceeded with private tutoring to help him, uh and the private tutor was able to get him to do grade 6 math, he's in grade 3 and supposedly at a grade 2 level. So clearly his needs are not being met in the classroom to help succeed.” – Deb</i></p>
<p>Lack of...: “He’s not a priority” (Wendy)</p>	<p><i>“I would say the high school, the guidance counsellors need to, um, communicate with the parents... I have emailed the guidance counsellor in the past, nothing back, like no communication between us. You need to respect the parents and communicate openly with them.” – Hannah</i></p> <p><i>“And I just feel like they don’t have enough training... they really don’t know... There are special needs teachers that do understand, but there are a lot of people who are not clear on everything.” – Susanne</i></p> <p><i>“...they just told us a couple weeks ago that we needed a new psycho ed assessment done, we said ok. And they said "so we can put him on the list" and I said ok what does that mean. And she said "well he might have to get it by grade eight, he's not a priority." and I said well by grade eight he's going to be quitting school so that's not really super helpful...” – Wendy</i></p> <p><i>“I think to be fair to the school though, I don't think they don't have enough funding and stuff. So I think their [they’re] strapped, they don't know what to do. So I'm not blaming them entirely because I think it's part of the whole system, I think that they could be doing things better but I think they could get more help too, that they're not getting.” – Nancy</i></p> <p><i>“I think that the school has the ability and the resources, but the problem is there's lack of resources. You know, I think they have one social worker for the Catholic board” – Justine</i></p>
<p>School Staff: “It comes down to one person” (Wendy)</p>	<p><i>“He used to have some really good teachers, he has had the odd one or two that I can still remember that were just horrendous. They wouldn’t believe anything I said about him, they thought he was the worst thing ever, and um, you know I am glad I got to prove them wrong.” Hannah</i></p>

	<p><i>“And the reality of it is they don't, they don't give you support in the schools... some teachers are really good. And there's, the majority of the teachers are shitty.” – Cara</i></p> <p><i>“It comes down to one person...It comes down to one person who he's with most frequently and what they believe to be the truth or what they believe to be real or what they believe to be Jack choosing to act this way and Jack not having a lot of control over that” – Wendy</i></p> <p><i>“And it really is dependent on the teacher.... and their approach and their belief in whether or not you need to meet a child where they're at, right. And his teacher last year was phenomenal and she believed in him whole heartedly and what he could do and what he was capable of.” – Wendy</i></p> <p><i>“we had no idea other than the guidance counsellor at school who was very helpful. Um if it wasn't for her, we still wouldn't know why she is struggling, we would just think that it was social anxiety.” – Carolyn</i></p> <p><i>“I think it's a result of lack of funding and lack of resources money and I think from a teacher's perspective um I understand they have a very hard job specially nowadays and I have respect for all teachers because um it's difficult” – Justine</i></p> <p><i>“A principal, principle can make or break a school. They can either teach mental health and about disabilities or they can shut it down and put it on the back burner and not make it a conversation.” – Justine</i></p> <p><i>“school itself seems too busy. His guidance counsellor is awful. Um, he – there was no transition for him” – Brenda</i></p>
<p>Effects on Children: “...he was really struggling” (Vickie)</p>	<p><i>“I said ‘well he needs more interaction with regular kids’, that is one of the main reasons I didn't want him in a congregated class” – Susanne</i></p> <p><i>“And so, she would sit there by herself, aware that she was different and aware, she's aware now that she's alone. With her toys and her brushes and people making fun of her.” – Cara</i></p> <p><i>“That comprehension isn't quite there. And he's like “well that's stupid and I feel stupid because I'm still learning math that I learned in grade five instead of grade nine.”” – Vickie</i></p> <p><i>“last semester probably about a month and a half, two months in, um he started getting really, his anxiety levels were skyrocketing. Um he was really struggling” – Vickie</i></p> <p><i>“every single day he'd come home, he was crying, he wouldn't go to sleep at night, he started wetting the bed, he started um the anxiety level just went from like maybe 25% to 95%. He wouldn't leave our side, he wouldn't do sleepovers anymore.” – Justine</i></p> <p><i>“I can tell you right now my son for sure feels that everyone in that school does not like him. And that's because I've been called sometimes twice a week, telling</i></p>

	<p><i>me my son is bad, not once have I ever heard him doing a good thing. I'm always called for negatives.</i>” – Justine</p>
<p>Effects on Mothers: “...it’s overwhelming” (Nancy)</p>	<p><i>“I end up being mom and teacher.”</i> – Susanne</p> <p><i>“Steve was the only autistic kid they had at his elementary school. Um, and the first autistic kid the school speech therapist ever had. So I was actually teaching them, which was frustrating [laughs] and not well received.”</i> –Brenda</p> <p><i>“It is difficult for me to find work at the moment because she's on shortened days at school. so I'm just sort of struggling with school issues... that's really where I think most of my issues lie, relating to the school.”</i> – Nancy</p> <p><i>“And there was nothing I could do. I couldn’t do anything for her.”</i> – Cara</p> <p><i>“Be your child's advocate and don't back down. You don't have to be their friend, this isn't about being friends, it's about getting the best possible level of service for your kid. Because if you don't do it, they're just going to, it's one less that they have to worry about. Then they can go onto the next one and deal with the next squeaky wheel.”</i> – Cara</p> <p><i>“What breaks my heart is that I think that Jack's out there in the school world for example, lost, scarred, confused, sad. And I can't control that.”</i> – Wendy</p> <p><i>“I get very emotional.... Every day you are being told something that is going wrong at the school, so it's overwhelming.”</i> – Nancy</p> <p><i>“How many people do I need to bring into the school to pay to come and to talk to you and say that this is what my son needs to succeed before your gonna do it?”</i> – Deb</p>

Discussion

Emerging themes indicated distress among mothers raising autistic children and highlighted challenges while navigating the school system. Concerns existed with regards to unrealistic expectations at school, lack of support and resources at school, and limited understanding of staff members, which all contributed to negative effects for autistic children and their mothers. The findings in this study reflect some of the challenges experienced by mothers described in existing literature (Brown et al. 2021; Brewer, 2018; Cappadocia et al., 2012; DePape & Lindsay, 2016). These challenges are symptoms of the continued oppression and stigmatization of autistic children who do not fit within the expectations of educators (Hodge et al., 2019).

The review by Danker et al. (2016) uncovered eight themes about the experiences of autistic children at school by comparing studies on the wellbeing of typically developing students to that of autistic students, from the perspectives of the students. The existence of positive relationships and a lack of negative relationships with peers and educators were essential in fostering a sense of wellbeing at school. It was evident in the narratives of the mothers included in our study that these positive relationships and interactions with teachers, school staff and peers were lacking

from their children's school experiences. School staff influenced children's successes due to the sheer amount of time spent together (e.g., schoolteachers) or views on inclusion within the school (e.g., principals). Danker et al. (2016) also listed sensory concerns, anxiety, social engagement difficulties, and fear of failure as school concerns for autistic children, which were also concerns listed by mothers in the present study.

Attitudes of non-autistic peers have been integral to the experiences of autistic children at school. In their review of 17 studies, Williams et al. (2019) surmised "inclusive mainstream settings may currently accentuate many pupils with [Autism]'s sense of being 'different' from [typically developing] peers in a negative way" (p. 24). Peer relationships and school accessibility could negatively affect student self-esteem, self-worth, and mental health (Hodge et al., 2019), which was supported in the present study. Some concerns could be addressed, namely the school environment and culture. For example, mothers discussed that their children were self-conscious about being different in the classroom, so it might be helpful to implement strategies for the whole class rather than singling out one child, while also creating a culture of awareness and acceptance of autistic peers. Wendy's son required activity breaks, but he did not like how breaks made him different from his peers. Physical activity breaks are a highly effective learning tool and would benefit all pupils (Watson, et al., 2017; Resaland et al., 2016; Camahalan & Ipock, 2015); therefore, the teacher could implement the break for everyone, rather than for just one child.

Research has indicated that principals have been instrumental in fostering support for autistic students (Williams et al, 2020), which could reduce stressors experienced by mothers. Unfortunately, principals in the present study were discussed as affecting school experiences more negatively than positively. Through interviews with 32 teachers, Williams and colleagues (2020) uncovered strategies that could be employed by principals to enhance the school environment for autistic pupils: professional development (e.g., of educators), resource allocation (e.g., funds for materials), and accommodating needs (e.g., adapting school procedures). The authors stressed the importance of principals' openness to and understanding of the unique needs of autistic students, "...viewing accommodations to meet those needs as a positive adaptation versus an inconvenience or negative occurrence." (Williams et al, 2020, p. 11).

Not only were principals integral to the education experience, but also paraeducators such as school counsellors. Through interviews with seven counsellors who worked with autistic children (among others), Gallo, Self, and Raush (2016) found they "*are in the ideal position to advocate for their students*" (p. 170), suggesting counsellors may be able to improve day-to-day experiences at school for autistic students, but also alleviate advocacy roles for parents. These results have been mirrored in the present study; in some cases, counsellors contributed to positive school experiences but in others they contributed to negative experiences. This emphasizes the need to provide autism-related and autism-informed education to not just teachers, but counsellors as well.

Recommendations

Undoubtedly, mothers of autistic children need supports as they navigate the school system to ensure their children receive the education they deserve. Note these recommendations are based on the experiences of 11 mothers who all identified as white and as women. When exploring and implementing various supports, it is also crucial to consider how to support families during and

following the COVID-19 pandemic. The pandemic compounded school-related challenges for autistic children and their caregivers. Caregivers of autistic children were expected to facilitate online learning while balancing regular work and home responsibilities, leading to overwhelm and burnout for caregivers, and learning difficulties for children (Mohammad et al., 2022). These concerns were exacerbated for ethnically diverse families (Neece et al., 2020). Future research should examine parent's experiences to understand which strategies were helpful in supporting autistic children's education. Moving forward, increasing communication between the school and parents of autistic children is paramount, so families, teachers, and principals may work towards similar goals. This communication could occur via parent teacher meetings, regular phone calls, email correspondence, and letters home to the family.

From a school perspective, staff should engage in further education about autism stigma and how to be accepting of all pupils. Such training should be developed and implemented alongside autistic students to ensure its effectiveness and relevancy. An aspect of this training should consider how teachers can adapt their current teaching practices to accommodate and embrace diverse learning needs. While some changes may not always be possible for teachers or principals (e.g., smaller class sizes to reduce stimuli), others could take place more easily (e.g., providing visual instructions and schedules where possible). Extracurricular options, such as tutoring and autism groups were discussed as positive by mothers in the present study, and therefore would be worthwhile to pursue in future research and/or practice. Autism-specific social groups may also increase sense of belonging for autistic pupils and reduce the need for autistic children to mask while they are at school (Hodge et al., 2019).

It will take time for societal changes to occur. In the meantime, increased funds are needed to (1) hire more educational assistants and resource teachers at schools, (2) reduce class sizes to increase individualized attention and reduce the load placed on teachers, and (3) incorporate more education into teachers' colleges regarding critical disability theory. Supplemental autism courses are available to teachers in Ontario, but at a cost. While the expense of these changes may appear substantial, the cost benefit analysis of Individualized Education Plans by Stapleton et al. (2015) exemplifies the potential return on investment for students in need of additional support at school. The suggestions above are merely the tip of the iceberg when it comes to fostering inclusive attitudes toward autistic children in the school system.

Limitations

A few limitations should be considered in the interpretation of results. First, interviews were conducted by three researchers, which could have influenced data quality (e.g., differing interview techniques). To mitigate this, interviewers used the same interview guide, and all four authors independently and collectively interpreted the results. Questions from any author were posed in member checks to ensure all interview questions were addressed adequately. Further, the three interviewers were all trained by the same supervisor, thus utilizing near identical methods.

Secondly, autistic children, teachers, and principals were not included. The themes discussed in this paper emerged from mothers' descriptions of their children's school experiences. While mothers provided rich descriptions of the school system, drawing on conversations with their children, schoolteachers, and principals, these findings did not include the voices of autistic

children themselves. Studies exploring the challenges of autistic students through firsthand perspectives are warranted.

The third limitation is the study sample. While homogenous, this research only included white participants who identified as women and mothers. There are important suggestions based on their experiences; however, people of other identities may have additional and/or different perspectives on the Ontario school system. Future research should include the voices of black, Indigenous, and people of colour who are autistic and/or caregivers of autistic people, as well as a diversity of gender identities. It also should include the voices of students and school staff, especially as the school system undergoes significant turbulence with the COVID-19 pandemic.

Future Considerations

While these interviews were conducted prior to the COVID-19 pandemic, families have faced increased strain because of virtual and remote learning (Cachón-Zagalaz et al., 2020; Lee et al., 2020; O'Sullivan et al., 2021). For some, this online environment is less conducive to learning and has increased the gap between autistic children and their peers, while for others, remote learning has been more effective. The changes suggested above should be implemented immediately to address the complexity of virtual learning for autistic children and considered when returning to school post-pandemic. The devastating circumstances of the COVID-19 pandemic may have a silver lining by providing an opportunity for policymakers to reconsider the Ontario school system and implement positive changes moving forward.

Conclusion

The present study aimed to explore lived experiences of mothers raising autistic children, specifically with respect to the education system. Based on 11 interviews with mothers of autistic children, the current school system may not meet the needs of autistic students. Mothers conveyed that they and their children struggled as limited resources were available to adequately support their needs. Future research could explore how the experiences of autistic students may vary among those in elementary school vs. high school. It would also be important to explore perspectives of school staff (e.g., principals, teachers, counsellors), autistic students, and other caregivers (e.g., fathers). By sharing mothers' experiences, the authors hoped to increase awareness about challenges associated with the Ontario school system and to provide suggestions for immediate implementation.

Key Messages From This Article

Autistic People: You deserve a quality education, in addition to accessible and inclusive learning environments.

Professionals: While there are limits within the school system, it is paramount to focus on the skills and abilities of autistic students, rather than perceived limitations.

Policymakers: Supports are desperately needed for autistic students and their teachers*, including neurodiversity training for educators, increased educator to student ratios at schools (e.g., educational assistants, resource teachers), and policies for inclusion across school boards.

**Note: These suggestions are based on a homogenous sample of affluent white mothers of autistic children and may not address needs of families experiencing multiple types of stigma intersections, such as class, race, and gender.*

Messages clés de cet article

Personnes autistes : Vous méritez une éducation de qualité, ainsi que des environnements d'apprentissage accessibles et inclusifs.

Professionnels : Bien qu'il existe des limites au sein du système scolaire, il est primordial de se concentrer sur les compétences et les capacités des élèves autistes, plutôt que sur les limites qu'ils perçoivent.

Les décideurs politiques : Les élèves autistes et leurs enseignants* ont désespérément besoin de soutien, notamment d'une formation à la neurodiversité pour les éducateurs, d'une augmentation du nombre d'éducateurs par élève dans les écoles (par exemple, assistants d'éducation, enseignants-ressources) et de politiques d'inclusion dans les conseils d'administration des écoles.

**Note : Ces suggestions sont basées sur un échantillon homogène de mères blanches aisées d'enfants autistes et peuvent ne pas répondre aux besoins des familles confrontées à de multiples types de stigmatisation, tels que la classe, la race et le sexe.*

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