WAVING A MAGIC WAND: SUPPORTS FOR FAMILIES RAISING SCHOOL-AGED CHILDREN WITH AUTISM SPECTRUM DISORDER AND FETAL ALCOHOL SPECTRUM DISORDER IN ONTARIO

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ABSTRACT

Background and Objective

The purpose of this paper is to examine the experience of parents raising children with Fetal Alcohol Spectrum Disorder (FASD) and Autism Spectrum Disorder (ASD) in the middle childhood stage of development. Furthermore, this research investigates parents' formal and informal support needs as they adapt to the demands of raising their children.

Material and Methods

Twenty-six parents of children with FASD and ASD who reside in Ontario, Canada completed the Family Resource Scale, the Family Crisis Oriented Personal Scales, and participated in semi-structured interviews informed by the Family Adjustment and Adaptation Response model.

Results

Using Thematic Analysis, 4 major themes were identified: (1) difficulty with the qualification for services; (2) difficulty with service availability; (3) formal supports; and (4) informal supports. The findings indicate that although there are services (e.g., respite care) available in Ontario, parents do not perceive there to be enough services to satisfy their family's needs.

Conclusion

This study demonstrates that supports need to be tailored to each child's individual needs. ASD and FASD both occur on a spectrum, and available resources should reflect that diversity. Considerations and future directions for ASD and FASD-related family research are discussed.

Key Words: *fetal alcohol spectrum disorder; autism spectrum disorder; mixed methods; families; support*

Research focusing on families of children with developmental disabilities is crucial for ascertaining what supports are most useful (e.g., support groups) for parents to adapt to the demands on the family, as well as to help discern the needs of those families.[1] Raising children with developmental disabilities can have a positive impact on the family while also posing some unique, disability related challenges.[2,3]

Supports for families of children with developmental disabilities have been widely regarded as facilitative for family adaptation.[4–6] These supports fall under 2 general categories: (1) formal support services, defined as professional or paraprofessional services and/or interventions (e.g., counselling, respite care, parent support groups[5,7]); and (2) informal supports, defined as emotional backing or practical aid provided by family members and/or the larger community.[8] Parents of children with developmental disabilities have reported that both types of supports have been useful for managing their children's needs.[9]

Social support and respite care have both been associated with decreased levels of perceived parental stress and parents are requesting these services, especially during times of transition.[10–12] Social supports are one of the most commonly discussed resources in developmental disability literature, and evidence has shown that it can have a positive impact on parents both psychologically and physically.[6,13] In addition to reducing stress-related physical symptoms, such as high blood pressure, the alleviation of stress connected to social supports has improved parents' personal sense of general mental wellbeing.[13,14] High parental marriage quality and the associated positive social supports have also been shown to increase parents' sense of wellbeing, and it is therefore important that parents take the time to maintain their relationships.[15] In this case, parents can turn to respite care, where a worker may come into the home or have the child stay in a facility for 30 days or less.[16] Respite care has been shown to have a lasting positive effect on parents' psychological wellbeing, much like social supports.[10,12] However, parents report difficulty accessing these formal services due to confusing service systems and failure to meet the specific service requirements, such as acquiring a formal diagnosis for their child.[3,16,17]

Formal supports also exist specifically for children with developmental disabilities, and are frequently accessed by them.[18,19] Individuals who have received early services and interventions have been found to have better long-term outcomes than those who received them later in life.[20] Early intervention (i.e., with these supports) has been shown to be particularly important for individuals with Fetal Alcohol Spectrum Disorder (FASD) and Autism Spectrum Disorder (ASD), in order to promote better communication skills and prosocial behaviours.[21,22]

FETAL ALCOHOL SPECTRUM DISORDER AND AUTISM SPECTRUM DISORDER

FASD and ASD are neurodevelopmental disabilities, and individuals with these diagnoses typically require lifelong supports. Individuals who have either disability may qualify for special educational support services, such as individual education programs (IEPs), because their related symptomatologies are listed within the Ontario education system's 5 categories of 'exceptionalities' (i.e., behavioural, communication, intellectual, physical, or multiple[23,24]). School boards in Ontario must develop an IEP for each student with identified exceptionalities and have the discretion to develop IEPs for students who are not identified as "exceptional" but who are receiving special education services.[25] Students with FASD may potentially touch on multiple, if not all, exceptionalities outlined by the Ministry of Education. Often students with FASD are inappropriately placed in the behavioural category because these exceptionalities do not accurately capture the brain-based impairments associated with FASD. A 2016 Ministry of Education Special Education Update indicated that special education for students with FASD is a part of the Special Needs Strategy, which aims to provide individualized supports for those individuals through early screening, assessments, and interventions (e.g., school placements).[26] However, more concrete practices, program planning, instructional strategies, and tools and techniques are available for teachers who have students with ASD in their classrooms.[27–29]

FASD is a diagnostic term that encompasses a continuum of symptoms, such as executive functioning deficits, learning disabilities, and mental

health challenges, resulting from in utero exposure to alcohol.[30] FASD has a prevalence rate of approximately 4% of the Canadian population.[31,32] ASD is also a clinical diagnosis, included in the current Diagnostic and Statistical Manual Version Five (DSM-V) as Autism Spectrum Disorder.[33] ASD has a prevalence rate of 1% of the Canadian populace, and is currently characterized by 4 main criteria: persistent deficits in social communication, restricted and repetitive patterns of behaviour, the behaviours must cause clinically significant impairment, and have an onset during the early developmental period.[33] Like FASD, ASD occurs on a continuum and ranges from mild to severe.

The broad spectrum of behaviours exhibited by individuals who have ASD and FASD mean that they require a range of services that are tailored to each individual.[3] For example, individuals with severe ASD often manifest more maladaptive behaviours (e.g., aggression) than individuals with mild ASD, and therefore require different behavioural interventions from their mildly symptomatic counterparts.[34] Neurological disorders, such as ASD and FASD, are also commonly comorbid with other disorders, such as intellectual disabilities, which require their own respective supports and interventions.[33] The unique needs of individuals with ASD and FASD can have a significant impact on the family.[3,18,35]

Severe ASD and FASD-related symptoms are considered contributing factors to some of the highest levels of perceived parental stress in the literature.[3,36,37] For example, high levels of perceived parental stress are thought to be related, in part, to the high frequency of maladaptive behaviours associated with each disorder during childhood.[3,35,38] Individuals who have ASD or FASD often share similarities in communication and social deficits, which are also linked to higher levels of perceived stress in parents.[39,40] Additionally, children with these disorders are often highly dependent upon their parents throughout their lifetimes.[3,19,41]

Although FASD and ASD have some similarities with regards to behaviour (e.g., externalizing) and child life (i.e., possible lifelong dependency) outcomes, research evidence indicates that there is a paucity of available supports specifically for individuals with FASD.[3,42] Ontario, in particular, has been cited as lacking in FASD awareness and supports to the extent that the Provincial Government of Ontario has recently released an FASD strategy for the provision of FASD-related services.[43,44] Individuals with FASD may be lacking in available services, but parents of children with ASD and FASD both report similar stressors including the diagnostic process and challenging externalizing behaviours.[3]

MIDDLE CHILDHOOD

A child's transition into middle childhood (ages 5–12) presents new stressors, such as a necessity for appropriate social skills in a structured school environment and the potential for bullying victimization, resulting in a need for formal skill building services.[45,46] Research has shown that families of children with disabilities in the middle childhood cohort have had mixed levels of success with adapting to raising their children, resulting in different levels of perceived parental stress.[47,48] The varying adaptive outcomes shown in longitudinal studies appear to be due to differing individualized stressors, such as disruptive child behaviours and a lack of resources in early childhood.[47,49] Conversely, parental optimism has been highlighted as a protective factor for familial adaptation, and can be promoted through formal support services.[50]

Previous research has shown some similarities between families of children with FASD and ASD in regards to the services that they have used. For example, Ontarian parents of children with either of the 2 disabilities discussed a need for the education of medical professionals and the timely diagnosis for services.[2,3] The present study will expand on these findings, with a focus on what supports parents require and what supports they actually use. To the authors' knowledge, there are no other mixed methods studies regarding the supports of families of school-aged children with FASD and ASD in Ontario. Resources, such as support services, have been highlighted as important for parents' long-term adaptation throughout middle childhood.[47] Therefore, the purpose of this study is to identify the experiences of families raising children with FASD and ASD, and to examine their formal and informal support needs as they adapt to the demands of raising their children in middle childhood.

METHODS

A mixed methods research design was employed, which entailed the gathering and integration of both quantitative and qualitative data.[51,52] The advantage of mixed methods is that it allows for a greater degree of trustworthiness and facilitates a superior depth of topic examination.[51–53] The mixed methods analysis presented here is a convergent parallel design, where questionnaire and interview data were analyzed individually and then compared and contrasted with one another.[51] The results are presented in an embedded format, whereby the quantitative data supports the qualitative themes.[52] The specific analyses performed are described below. This study received ethical approval from the Laurentian University Research Ethics Board (2013-09-03).

PARTICIPANTS

A total of 26 parents were recruited through FASD and ASD support networks, as well as local FASD and ASD agencies situated across Ontario, Canada. Emails were sent directly to agencies and contacts, which directed participants to contact the lead researcher should they wish to participate. The research team also used a respondent-driven sampling recruitment method, where they contacted known individuals for assistance with recruitment.[54] The data were gathered as part of a larger family project; however, only the data for parents of school-aged children were examined for this study. "Parents" encompassed parent dyads that were adoptive parents, step-parents, or birth parents (all referred to here on in as parents). All participants were part of a parent dyad and they were able to participate in the interviews either together or as individuals. Pseudonyms were used to protect the identity of participants. The selection of parents from the larger project's data set was conducted by age-matching children with FASD and ASD, excluding children with concurrent diagnosis. Due to a limited pool of data for parents of school-aged children with FASD within the greater data set, children were age matched based on age groupings within the school-age range. Please refer to Table 1 for the age groupings and number of children with each disability within each age group. All parents had at

TABLE 1 Age-Matching Groups

Years of Age	Type of Disability	
	FASD n	ASD n
5–6 Years, (n)	2	4
7–8 Years, (n)	4	3
9–10 Years, (n)	5	5
11–12 Years, (n)	0	1
Total	11	13

least one school-aged (i.e., 5–12 year old) child with FASD or ASD and were randomly selected. Parents ranged in age from 28 to 71 ($M = 40$). For additional demographic information please refer to Table 2.

QUALITATIVE INTERVIEWS

Semi-structured interviews were conducted with parents of children with FASD or ASD. The interviews were administered following an inductive strategy, using a basic interpretive approach, which endeavours to understand how individuals make meaning of a given situation.[55] Participants were asked 22 open-ended questions, and prompts were used when necessary. An example question is "If you could wave a magic wand, what supports would you like?" Participants chose the time and the location of the interview, at their convenience (e.g., coffee shops or family homes). Parents also chose to participate in the interview together or separately according to their personal preferences. Parents were contacted via email when necessary for any follow-up questions that arose during the analysis.

The interviews were analyzed using a 6 phase standardized model of Thematic Analysis, whereby researchers searched for recurrent patterns of meaning across the data set.[56] A theoretical approach was used, whereby the Family Adjustment and Adaptation Response (FAAR) model informed the interview questions and analyses.[56] All interviews were audio recorded and transcribed verbatim. The transcriptions were reviewed several times to promote familiarity

TABLE 2 Participant Demographics

	FASD		ASD	
	n=13		n=13	
Parent Characteristics	Mdn [IQR]	n (%)	Mdn [IQR]	n (%)
Age				
Male	39.5 [33–51.3]	5 (61.5)	36.0 [31–42.5]	6 (46.2)
Female	42.0 [33.8–54.5]	8 (38.5)	38.5 [31.25–42.5]	7 (53.8)
Marital Status				
Married	–	11 (84.6)	–	13 (100.0)
Common Law	–	2 (15.4)	–	–
Family Type				
Adoptive Families	5	5 (55.6)	–	9 (100.0)
Biological Families	1	1 (11.1)-	–	–
Other Family Types	3	3 (33.3)	–	–
Child Characteristics				
Age				
Male	7 [6.0–9.5]	5 (45.5)	6.5 [5.0–9.75]	12 (10.9)
Female	8.5 [7.75–9.25]	6 (55.5)	12 [N/A]	1 (9.1)
Number of Children with ASD or FASD per Family				
One	–	6 (66.7)	–	5 (62.5)
Two or more	–	3 (33.3)	–	3 (37.5)

with the data. Notes were made during the reviewing process pertaining to possible codes and/or themes. The transcriptions were then reviewed again, and all relevant information was given a clearly defined code. The codes were then clustered into themes. Intra-thematic codes showed evidence of internal homogeneity, and inter-thematic codes showed external heterogeneity of meaning.[57] After the themes were clearly defined, they were labeled using quotations taken directly from the interviews, which augmented theme validity.[53] To promote trustworthiness, an independent data analysis of the interview transcripts was conducted separately by 3 members of the research team. The research team then met to discuss their themes and to reach a consensus on the final themes presented here. Additionally, an audit trail was established that included descriptions of the process of developing the codes and themes, of the exclusionary/inclusionary theme criteria, and of the chosen quotes for each theme. Member checking was accomplished by emailing participants, providing them with a short theme report, and requesting their feedback on the themes.

QUESTIONNAIRES

All participants completed a short demographic questionnaire including the information listed in Table 2. Participants completed the Family Resource Scale (FRS)[58,59]; and the Family Crisis Oriented Personal Evaluation Scales (F-COPES)[60]. The documents were provided to participants in person or were mailed via Canada Post. Further details on each scale are provided below.

The Family Resource Scale (FRS)

The FRS measures the adequacy of resources and the needs in households of families with young children.[58,59] The questionnaire contains 30 items assessing physical and human resources such as food, shelter, financial resources, transportation, time, and health care. Parents must rate the adequacy of each resource on a Likert scale, with the answers ranging from "not at all adequate," "seldom adequate,"

"sometimes adequate," "usually adequate," "almost always adequate," and "does not apply." An example item is "Money to buy necessities."

The Family Crisis Oriented Personal Evaluation Scales (F-COPES)

The F-COPES was administered to identify problem solving strategies used by families in difficult situations.[60] The F-COPES contains 30 items assessing 5 areas of coping behaviours related to: Acquiring Social Support, Reframing, Seeking Spiritual Support, Mobilizing Family to Acquire and Accept Help, and Passive Appraisal. Higher scores indicate higher levels of coping and vice versa. The questions are provided on a five-point Likert scale, ranging from "strongly disagree" to "strongly agree." An example question is "When we face problems or difficulties in our family, we respond by: Showing that we are strong."

QUANTITATIVE ANALYSIS

Triangulation involves the comparison of different sources of data for the purpose of providing additional supporting evidence.[51] This method was used in this study. For example, a theme was presented with an applicable questionnaire item from each scale included in this study. Descriptive statistics were presented in an embedded format. The embedded format was selected given the qualitative emphasis of this paper through interviews, and the function of the quantitative data to provide further theme support.[51] The small sample size, the ordinal and categorical format of the questionnaire data, and the exploratory nature of the study limit many possible statistical analyses, thus resulting in a descriptive study.

RESULTS

All parents identified significant family assets, including personal resources and supports external to the family unit. Through the use of Thematic Analysis, 4 major themes emerged from the resource-related issues raised by parents during the interviews.[56] These themes included: (1) difficulty with the qualification for services, (2) difficulty with service availability, (3) identified areas of improvement for formal supports, and (4) identified areas of improvement for informal supports. The questionnaire data supported and provided further evidence for these 4 themes.

Qualification for Services and Service Availability

Parents reported difficulty with having their children qualify for services, and difficulty actually accessing those services once their children were deemed qualified (e.g., respite care). All parents spoke about the necessity of a formal diagnosis for a greater ease of service access. Parents of children with ASD highlighted the importance of specific and adequately written psychological reports, and their impact on school service acquisition. Parents of children with FASD, however, stressed the need for FASD recognition in all Ontario schools. Nonetheless, the children with FASD and ASD who did manage to qualify for their desired services were commonly placed on extensive waiting lists.

"In Order To Get Proper Services, They Needed A Firm Diagnosis": The Necessity of a Diagnosis for Service Access

Parents discussed how services such as respite care services, school-related services, and therapeutic services required a formal disability diagnosis for child admittance. According to the F-COPES, 88% of parents reported seeking assistance from community agencies and programs designed to help families in their situation; however, not all children qualified for those services. Ethan, a father of a five-year-old son with ASD, described the problem:

> When you don't have the diagnosis in your hand, there's this huge roadblock up in front of you. And then it doesn't matter if you're in school or you're in private . . . There's this big wall that goes up and people go, "we're not talking to you unless you come . . . with that piece of paper." You come knock on the door and you've got that [diagnosis], no problem.

Similarly, Karen, a mother of 2 sons with FASD said "We can't get them extra help unless they have a [formal FASD] diagnosis."

In addition to the need for a formal diagnosis, parents of children with ASD discussed a need for professional diagnostic precision when attempting to access school system services. Psychological reports were described as crucial to the education system's service decision making process. Mark recounted the impact of subtle differences in how children's psychological assessments are written: "If you're looking into school services, if they write a certain

phrase, they won't give you the right services." Jackie, a mother of 4 children with ASD, described the significance of wording when emphasizing her family's needs in order to avoid a minimization of their family's experiences: "You have to give the agency the worst possible day ever so that they'll see and believe you that there are issues – if you write that it's not so bad, they'll say that you're lower on the priority list and your funding won't be that great." Parents also noted that including the language of a mild or moderate diagnosis in reports created a barrier to accessing needed services. Carla, a mother of a child with mild ASD, spoke of her experiences: "What are they gonna offer and does he even qualify? Because he's mild and, oh well, we deal with the more severe cases first. Fair enough, but in the meantime, I'm still having to deal with this."

In contrast to parents of children with ASD who have established supports both in the community and the school system, several parents of children with FASD discussed difficulties with getting the school boards to acknowledge their children's FASD as a disability at all. Veronica discussed the need for "getting the school to recognize it because our school board doesn't recognize FAS[D]." Leslie also described how "FAS[D] is still not really recognized as a disability in Ontario." A lack of a diagnosis also makes it difficult for teachers to form a plan of action. Nina, a school teacher and mother of a daughter with FASD, described the need for an FASD diagnosis in the school system: "it's really crucial for the teachers too. To have something that they can hang their hat on and say this is the child's problem, and so then you can get all the help that you can." Other children's schools did acknowledge FASD, resulting in successful access to services. For example, Jodi described her experience: "It was a big deal telling the school and they kind of just took it and ran with it on their own." Patricia was thrilled when her doctor wrote a report specifically for her daughter's school: "he put down in her report, this child needs x, y, and z. She's gonna need it consistently at school. She will need more supervision than the average child. She will need an EA [educational assistant]." Because of the formal FASD diagnosis, she received the services she requested.

"The Waiting Lists on the Different Types of Services are Crazy": Extensive Waiting Lists

In addition to the challenges receiving a formal diagnosis, parents reported that they felt the waiting lists for services for their school-aged children with both FASD and ASD were extremely lengthy. Services such as diagnostic assessments, respite care, and therapy can take years for parents to gain entry. Katrina, a mother to a son with ASD, described her experience when seeking out financial assistance for services: "I was told there was a waiting list and I said, as in years or months? She's all – 'I wouldn't count on months.'" Several parents turned to private services and paid for them out of pocket in order to gain access to some help more promptly.

Seventy-three percent of parents of children with ASD described being placed on an unreasonably long waiting list during their interview. Roger, a father of a son with ASD, recounted being told that the waiting list would be about 2 years for his son. Jackie also described her experience with waiting lists and said "well it wasn't hard to access [the services], it was just hard to get the services and get off the wait list." The wait list was a concern for parents who understood the importance of early intervention for ASD. Anna reported feelings of frustration towards the overburdened system: "I'm supposed to wait and do nothing, like a lot of parents do nothing. I can't do nothing." Some parents were particularly concerned about long waiting lists for Intensive Behavioural Intervention (IBI), which is an intensive application of Applied Behaviour Analysis and is currently the gold standard for ASD behaviour management.[61] For example, Melanie, who has 4 children with ASD, reported: "And I don't know how long that list is, you know? They're cutting back with IBI and stuff like that." She went on to say that, if she could wave a magic wand, she would put her child "in IBI tomorrow." Ethan and Carla waited for a year for IBI before discovering that their son did not qualify for IBI, and so they resorted to paying for private services, like speech therapy, for their son. Ethan explained that he couldn't "wait anymore. He needs it now."

Several parents of children with FASD expressed a similar dissatisfaction with the long wait lists. Leslie described her process procuring services for her

children post diagnosis: "Everything was fairly slow moving . . . 8 to 10 months to a year." Nonetheless, once parents received the services, they were not always adequate or helpful. Jodi reported spending the same amount of time waiting for counselling sessions, which turned out to be frustratingly insufficient. As she described, "he was on the wait list for about a year and then they get 10 sessions and that's it." During the interview Patricia was asked what services she would desire if she had a magic wand and she responded: "I would banish the waiting lists and things like that. We've been on a wait list for almost 4 years for the one particular special service at home." The wait lists functioned, in part, as motivation for both groups of parents to take on the role of parent advocate and push for the services their children require.

FORMAL SUPPORT

Despite parents' skills at advocating on behalf of their children, parents of children with ASD and FASD asserted that there are some formal supports still lacking in Ontario. Parents reported a need for more child supervision outside of school hours and during school holidays.

"They Need Supports Afterschool, Clubs, Places To Go": More Child Supervision Services

Although parents were receiving some respite care, they discussed a general need for additional respite care services. Specifically, some parents in both disability groups reported difficulties finding supervision for their children between the end of their child's school day and the end of their work day. Parents also reported struggling to find activities for their children during school holidays. Nina described her children's extended school vacations, during which she is forced to obtain extra supervision for them: "Summertime, Christmas holidays, maybe she could have one day off or something, but a whole week of days off . . . that are just totally empty are the biggest challenge I see right now."

Parents did report receiving some respite care services to help with those unsupervised time periods, but reported that the number of hours received were inadequate. Melanie described her "luck" receiving 3 nights of respite care for her 3 children: "That's a

lot compared to a lot of people when you have just one child that has Autism. I think you get, what, a half hour a week?" Shane, a father of a daughter with FASD, highlighted respite care and the importance of adequate services "to give the family a break". As Shane elaborated, adequate respite care was important "because I think everybody needs a break from the intensity . . . just to . . . be able to have a normal meal would be really nice."

Some parents reported settling for supervision sources outside of formal respite care due to the lack of alternatives. For example, Rebekkah discussed a mediocre student-run afterschool program, saying that "I guess [the students] are cheap enough that they can have more." Leslie described turning to her parents for supervision: "I would love a babysitter who dealt with kids with special needs. So that I had somebody that I trusted, [aside] from our parents."

INFORMAL SUPPORT

All parents discussed a need for social supports, both internal and external to the family. Parents reported turning to friends and extended family with mixed results. The majority of parents discussed the importance of relationships with individuals in similar circumstances for advice and social support. Additionally, parents described their reliance on each other as a couple for both practical and emotional support.

"You've Always Got To Have Support.": A Social Network Is A Necessity

All parents described the need to turn to other individuals for support, including friends, family, and support groups. Parents highlighted the importance of empathy and practical advice from members within their social network. Parents also described negative experiences with friends and family who did not understand their children's diagnosis or related behaviours.

Parents found disability-specific networks (e.g., online forums, Facebook groups) and formalized support groups to be useful as a place to discuss their feelings and seek out advice. Parents described the value of having an outlet in which to vent. Anna described her online ASD support group: "We're all on Facebook so we can bitch back and forth to each other." Veronica also found her FASD online support

group emotionally helpful: "It's a website with . . . parents who have adopted FAS[D] children. If you're having a crappy day basically, you can just type, post, and . . . there's support." Nina attended an FASD support group in person with parents who shared similar life circumstances and described her general experience:

> I've gotten to know them . . . as friends now, and it's a very safe place to go and talk about what's going on in our family. That's where I learned a lot too, like hey, what's going on in our family, that goes on in other families as well, and we're not just crazy and you learn strategies to help.

In addition to support groups, parents turned to their family members for assistance. Rebekkah described relying on her father for child supervision: "So when he's here it really gives me and Roger an opportunity at night when the kids are sleeping, we could go for a walk, he's here in the house. We know that if the kids wake up everything's OK." Tracy shared a similar experience with her extended family who stepped in to offer her some respite: "They help, you know. My sister in law – Friday, tomorrow evening, she'll take her and have her until Sunday." Ethan described his son's love for his grandmother and aunt: "We lean on them most because they understand him, have patience with him, and he loves them to death."

Conversely, 4 parents of children with FASD described family members who did not understand FASD. Jodi reported her experience with her extended family: "It's awkward because they know that he has FASD but I don't know if all of them really know what that means and so they don't treat him accordingly." The FASD diagnosis changed Patricia's interactions with part of her family: "It changes . . . extended family dynamics. Some family members don't understand the diagnosis. Some people were super willing to read anything I gave them." Tamara's parents were receptive, but still didn't fully understand what she was really going through: "You can talk to them about it but they don't really understand the situation."

Parents of children with ASD also encountered misunderstandings about their child's disability. Katrina recounted the experience of telling her family that her child had ASD: "The initial response from everybody is – no – there's nothing wrong with him

because they all think, well, you know, handicapped kid and he doesn't look like it." Melanie described her experiences with her brother "who really doesn't care to know anything about Autism" and her extended family members who "assume your children are rude." Carol's family was similarly unsupportive: "I didn't talk to my family at all. I still don't talk to my family about it, because they don't . . . really truly believe that it's a true diagnosis."

The lack of consistent support from family and friends was also reflected in the questionnaire data. On the FRS, participants were asked to rate the extent to which they had someone to talk to. Forty-six percent of parents of children with ASD indicated that the extent to which they had someone to talk to was 'almost always adequate' (i.e., the highest point on the Likert scale), demonstrating that more than half of parents (54%) do not always have someone with whom they can share their concerns. Parents of children with FASD indicated that they required additional social support relative to parents of children with ASD, with 58% of participants indicating that they had someone to talk to either "sometimes," "seldom," or "not at all." Additionally, participants completed the F-COPES subscale Acquiring Social Support (ASS), which measures "a family's ability to engage in acquiring support from relatives, friends, neighbours, and extended family."[60] All parents of children with FASD and ASD scored within the average percentile range on the ASS subscale. The F-COPES results indicate that parents are generally able to access social supports within their families and the greater community; however, according to the FRS, parents still report requiring more fulfilling emotional support from their existing relationships.

In summary, parents discussed 4 major areas pertaining to the attainment and use of formal and informal services. Parents described how a formal diagnosis is necessary to qualify for services, particularly in the school system (e.g., EA), and how they were often placed on long waiting lists for these services. Parents also described important formal and informal services. Formal services such as child supervision were reported to be highly valued, but parents reported a need for the education of professionals in order to find these

resources more helpful. Finally, parents reported the necessity of informal supports, including the need to maintain a social network for practical, emotional, and informational purposes.

DISCUSSION

The present mixed methods study incorporated interview and questionnaire evidence concentrating on the support-related needs of parents raising school-aged children with FASD and ASD in Ontario, Canada. All parents endorsed social supports as essential for facilitating adaptation in relation to raising their children with ASD or FASD. Some parents discussed the emotional and practical support that family members offered, and how such support was associated with a decrease in perceived stress. The opposite was true of parents who encountered family members who were unsupportive. Parents described frustration with friends and family who did not understand their children's diagnosis. The reported need for social support is consistent with a large body of related literature,[9,14,15] as is the stress associated with a lack of social support.[62,62]

Despite parents' endorsement of social resources, it appears that parents were not able to adequately access them. Both the quantity and quality of social support are important for the reduction of perceived parental stress; however, all parents reported encountering relationship difficulties with friends and/or family over issues related to their children's FASD and ASD diagnoses.[64] Questionnaire data (i.e., FRS and F-COPES) indicated that parents of children with FASD had access to someone to talk to less often than parents of children with ASD, although more than half of parents from both groups reported that support was absent at least some of the time. This lack of social support may be due to FASD often being an invisible disability and the lack of general public knowledge surrounding FASD.[65,66] For example, when others do not understand an FASD diagnosis, parents are often blamed for their children's disability-related externalizing behaviours.[2,67]

In addition to the discussion surrounding supports for parents of children with FASD and ASD, there were also barriers regarding qualifying for services and service availability. Parents described

the need for a diagnosis and how difficult it can be for individuals with mild or moderate symptoms to procure a diagnosis required to obtain services. The difficulties reported surrounding diagnosis are consistent with previous research by Watson, et al.,[3] who reported that parents of children with FASD, in particular, found that services, including the education system, did not fully acknowledge FASD or did not know how to support individuals with FASD effectively. FASD is more difficult to diagnose and children with this disability are often coded under the catch-all behavioural category of exceptionality. However, ASD is included in the definition of one of the 5 exceptionality categories, communication, and has specific resources available for individuals with that diagnosis (e.g., applied behavioural analysis).[23,24] The acknowledgement of FASD as a disability in Ontario has been improving as the government has been working on the aforementioned province-wide strategy to address FASD and provide appropriate services through awareness, early screening, and training of professionals.[44] As a consequence of the roundtable report, which outlined common challenges faced by parents of children with FASD (e.g., screening and diagnosis), an education update was put forward asking schools to submit applications for additional services related to FASD and other developmental disabilities.[68] However, the FASD initiative is in its infancy stages, and whether or not these services will be delivered remains undetermined.

An additional challenge for families of children with FASD and ASD included a lack of child supervision services, such as respite and afterschool programs. The Ontario education system institutes week long holidays (i.e., Christmas and March break), in addition to a 2-month summer holiday, during which time parents require supervision for their children. Families of children with ASD and FASD face additional challenges when seeking supervision because disability related externalizing behaviours often require formal respite care rather than an informal local babysitter. Parents of children with problematic behaviours can also experience difficulties with their child's expulsion from respite care programs, further hindering their access to adequate supervision services.[69]

Addressing the aforementioned issues can help parents balance their demands and strengthen their capabilities, fostering adaptation in raising a child with a disability. Although most FASD interventions currently lack empirical evidence to support their effectiveness, there is research to suggest that early diagnosis before the age of 6 and early service involvement can reduce the likelihood or impact of adverse outcomes.[21,70,71] Additionally, it has been established in the ASD literature that prompt diagnosis and subsequent early interventions, like IBI, predict the most successful treatment outcomes.[72,73] Adaptation in middle childhood is important as early intervention at this time can have long-lasting positive impacts on families, potentially reducing the likelihood of additional challenges as these individuals transition into adulthood.[20,71]

CONSIDERATIONS AND FUTURE DIRECTIONS

The greatest strength of this study was the mixed methods design. The integration of the questionnaires with the interview findings contributed to themes with greater credibility than either body of data could provide alone. There were few items on the quantitative measures that corresponded with the analyzed themes, highlighting the importance of using both quantitative and qualitative data to gain a more complete picture of parents' experiences. Steps were taken to maximize trustworthiness of the data, including standardized interview training and the discussion of themes with other project researchers. Additionally, in order to be as transparent as possible, an audit trail was kept and member checking was employed. Participant feedback was positive and was confirmatory of the themes presented here.

A second strength of this study was the method of age-matching used for participant selection from the larger project's data set. Every family included in this study had at least one child with FASD or ASD whose age fell in the middle childhood range, ensuring that parents would have been more likely to have encountered similar age-related milestones of their children (e.g., their children attend school). Because of the similarity in their children's ages, parents were also exposed to comparable stressors, such as requiring more child supervision during school vacations.

Despite the rigour of the methods used, there were several limitations. The first limitation concerned the recruitment source, which consisted primarily of ASD- or FASD-specific online or community resources. Individuals who attended support or educational groups may have exhibited different personal characteristics than those who did not. For example, research has shown that individuals who attend support groups experience an increase in subjective wellbeing, mental health, and social support.[6,62,74] It is therefore possible that parents who regularly access community supports may adapt better to their children's disability than those who do not attend a support group. To eliminate any positive biases, it would be beneficial to conduct a study including more participants who have not accessed formal disability supports as they may not be as well adapted as parents who regularly use them.

The second limitation is that parents' socioeconomic status (SES) and level of education were not accounted for. Many parents either forgot or declined to respond to the items associated with SES and education level on the demographic questionnaire included in this study. SES and parents' level of education should be considered in future studies, as higher levels of both factors can positively impact children's level of functioning and life outcomes.[75,76] Parents with a higher SES are also more likely to have access to privatized services, such as tutors, therapy, or other types of formal supports, because they can afford to access those services.

A third caveat to this study is that the diagnostic criteria of ASD and FASD are constantly evolving.[30,33,77,78] For example, in the current diagnostic manual (DSM-V), ASD is considered to be on a spectrum, whereas there are separate diagnostic categories in the previous version (e.g., Asperger's). A similar change has occurred in the new Canadian guideline for FASD diagnosis, with the inclusion of FASD as a diagnostic term whereby individuals fall along a spectrum, as opposed to an umbrella term overarching other diagnostic categories (e.g., Fetal Alcohol Syndrome), among other changes (e.g., the deletion of growth as a diagnostic criterion and the

addition of an 'at-risk' category).[30] Qualification for services may have changed in accordance with the diagnostic criteria modifications, which may or may not have impacted parents' service experiences. Future research regarding the impact of changes in diagnostic criteria on service access would be beneficial as professionals shift to using the new criteria.

CONCLUSION

This study has demonstrated that supports need to be tailored to each child's individual needs. ASD and FASD both occur on a spectrum, and available resources should reflect that diversity. Parents of children with either disability acted as expert advocates for their children's needs and felt that formal services for child supervision were lacking. Parents also highlighted the necessity of obtaining social supports, whether it be through friends, family, or support groups. Although preliminary movements in policy have been made, such as the education initiative, parents have indicated a clear desire for further changes in Ontarian policy. Providing school-aged children who have ASD or FASD with the appropriate services will lead to more positive life outcomes and facilitate family adaptation as they progress through their child's developmental stages.

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CONFLICT OF INTEREST

None

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