



Mothers' Experiences of Obtaining a Diagnosis and Support for their Child with Autism Spectrum Disorder

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Abstract

Autism Spectrum Disorder (ASD) is a neurodevelopmental disorder associated with communication, social, and behavioural challenges. A challenge faced by parents of a child with ASD is the process of obtaining a diagnosis and services for their child. In this collective case study, we interviewed six mothers in a large Canadian city who had at least one child with an ASD diagnosis. We asked about their experience obtaining a formal diagnosis, support, and how they perceived their children's educational experience. Mothers highlighted the difficulties and barriers they encountered, as well the importance of support. Implications of such findings are discussed.

Key words: Autism Spectrum Disorder, diagnosis, intervention, school, public healthcare

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Introduction

Due to the high prevalence of Autism Spectrum Disorder (ASD) in Canadian society, and the associated stress amongst parents when receiving a diagnosis and searching for services, it is critical to understand the experience of families with an ASD-diagnosed child. Parents may be unfamiliar with ASD and its implications for themselves and their child, as well as what supports are available to them, and how to obtain the needed supports. As mothers tend to have more child-rearing responsibilities on a day-to-day basis (Padden & James, 2017), the purpose of our study was to provide the opportunity for mothers to voice their experiences, concerns, and perceptions of the diagnostic, intervention, and school experience for their child with ASD.

Understanding Autism Spectrum Disorder

According to the Public Health Agency of Canada (PHAC; 2018), ASD impacts 1 in every 42 boys and 1 in every 165 girls. Globally, it is estimated that 1 in every 160 children have an ASD diagnosis (World Health Organization, 2019). This neurodevelopmental disorder is characterized by atypical development in social interactions and communications, and the use of restricted and repetitive behaviours, activities, or interests (American Psychiatric Association; APA, 2013). Parents tend to notice early signs such as little to no eye contact, joint attention, or a lack of social interest between the ages of one and two (Locke et al., 2020; Zwaigenbaum et al., 2015). With time, delayed or regressed language development, odd play and communication patterns, and a continued lack of interest in social engagement is common, leading parents to seek a diagnosis and professional help (APA, 2013).

One alternative to the medical model, which is narrow in scope, is the biopsychosocial model that takes into account biological, psychological, and socio-environmental factors (Chown & Beardon, 2017). In this model, the significance of a formal diagnosis is maintained as it helps those diagnosed understand themselves and allows families, friends, and services to offer support. However, societal effects are also highlighted by acknowledging the complexity and heterogeneity of disabilities, which include socially constructed barriers that further limit individuals with a disability to function in society. This model stresses the importance of accommodating the unique needs of individuals with ASD and their families as the effects and implications of a diagnosis vary greatly (Carlsson et al., 2016).

The Impact of Obtaining an ASD Diagnosis

Mansell and Morris (2004) articulated a 4-stage model for obtaining an ASD diagnosis. First, parents enter the pre-diagnosis phase, which includes confusion about their child's behaviours, feelings of self-blame, and severe stress. Parents tend to notice signs of atypical development, such as the lack of affect or sharing of interests and objects, as early as 18 months (Zwaigenbaum et al., 2015). However, parents may be given false reassurances by pediatricians that their child will grow out of it or that as new parents their concerns are not legitimate (Locke

et al., 2020). A formal diagnosis is often provided before the age of six, which is the second phase (PHAC, 2018; Zwaigenbaum et al., 2015). Here, parents often experience mixed emotions; they may feel relieved that their suspicions were correct and their child's behaviours were not due to their parenting, and they can begin the process of accessing services (Bloch & Weinstein, 2009; Carlsson et al., 2016; Osborne & Reed, 2008). Parents also begin to realize the consequences this diagnosis has for themselves, their child, and the family unit, which has ramifications for the third stage of readjustment (Potter, 2016).

In the third stage, the entire family needs to readjust. Parents may feel depressed, angry, helpless, and fearful for themselves and their child's future (Bloch & Weinstein, 2009; Potter, 2016), more so than parents of typically developing (TD) children (Walton & Ingersoll, 2015). In line with family systems theory, the ups and downs of receiving a formal diagnosis, along with the difficult behaviours of the child with ASD, are bound to impact the family as a whole (Cridland et al., 2014). This period is often the longest and is followed by the final stage of acceptance, though positive and negative events are continuously experienced. Parents certainly want support in processing and adapting to a diagnosis, as discussed next.

Obtaining a Diagnosis and Support

The processes involved in obtaining an official diagnosis for one's child can be arduous and stressful. Typically, in the United States, Europe, Australia, and Canada, parents of children of ASD reported higher levels of stress than parents of neurotypical children (Barosso et al., 2018; Walton & Ingersoll, 2015) and of children with Down Syndrome and other intellectual disabilities (Abbeduto et al., 2004; Griffith et al., 2010). This remains true independent of symptom severity (Rao & Biedel, 2009), indicating there are other factors than child-characteristics impacting parental stress, such as finances and other responsibilities. Parents of children with ASD are also less likely to remain employed after obtaining a diagnosis, especially mothers (Maich et al., 2019). In a Canadian study, it was reported that 100% of fathers and 65% of mothers of TD children were employed full time compared to 79% of fathers and 44% of mothers of children with ASD (Watt & Wagner, 2013). It appears the process of receiving a diagnosis, as well as the aftermath, can be a comforting yet stressful time for families.

Evidently, the need for support during and after the diagnostic process is paramount; however, it is not readily available. Barelds and colleagues (2009) identified quality determinants of the services rendered that are important to parents of children with disabilities; specifically, accessibility of services and professionals, continuity and flexibility of services, and validity of the information provided. The literature suggests that parents in various jurisdictions (e.g., United States, United Kingdom, Canada) are generally dissatisfied with some determinants of services throughout the diagnostic and intervention process (Crane et al., 2015; Locke et al., 2020; Potter, 2016; Rivard et al., 2015).

Parents have reported dissatisfaction with how the diagnosis was delivered. Health care professionals tend to be blunt in their communication with parents, thus lacking sensitivity and understanding. Moreover, parents from the United Kingdom and the United States reported receiving minimal help at the time of diagnosis, in terms of services, organizations, and availability

of early intervention programs (Crane et al., 2015; Mansell & Morris, 2004; Osborne & Reed, 2008; Potter, 2016). As such, parents searched for information on their own and reported feeling overwhelmed by the amount of information they had to sift through independently (Brown et al., 2012; Locke et al., 2020). Similarly, when professionals provided parents with information, parents still felt overwhelmed as they did not have time to process the information and their emotions, or to formulate questions (Carlsson et al., 2016).

Families reported that continuity of services received is also mixed, as there is often poor communication between the various service providers and a high staff turnover creating difficulties for parents and families in the United Kingdom, Canada, and Sweden (Brown et al., 2012; Carlsson et al., 2016; Osborne & Reed, 2008). Continuity is pivotal not only for the child, but is also positively related to maternal psychological wellbeing (Hodgetts et al., 2017). The lack of it poses a problem for the child, parents, and siblings who are trying to adjust to a child with ASD while learning and teaching new skills to this child. Moreover, some families felt services did not provide enough help or it was provided too late to be optimally beneficial. In terms of education and in keeping with the Commitment-to-Success Plan, parents, school staff, and children are to be included in the establishment of an individualized education plan (IEP), which is to be adapted to the child's needs and capabilities. By analyzing the abilities and needs of a student, modifications can be made to minimize obstacles to their education. (Education Act, 2020). However, parents also described receiving assistance and advice from teachers, who may not be properly educated or trained (i.e., specialized courses in working with neurodiverse children) to deal with the child's behaviours and social abnormalities, perhaps also impeding the development of new skills (Mansell & Morris, 2004).

The Impact of Obtaining ASD Services on Parents

Interventions for children with ASD have shown effectiveness in improving cognitive abilities, communication skills, and symptom severity (Estes et al., 2019), which can have secondary effects on parental wellbeing. In line with family systems theory, a bi-directional relationship exists between parental wellbeing and child intervention outcomes (Karst et al., 2012), as discussed next.

Early intensive behavioural interventions (EIBI), a one-to-one structured treatment addressing core deficits of ASD, generalization, monitoring, and family involvement (Reichow et al., 2018), was effective in treating children with ASD, but also in enhancing parent knowledge, skills, and performance (Estes et al., 2019). Interestingly, the more hours of EIBI a child receives (up to 40 hours a week) is associated with a decreased parental stress, which is further associated with improvements in child outcomes. The reverse has also been demonstrated, in that child outcomes were not as salient when parental stress was high (Osborne et al., 2008). Parent-implemented behaviour modification has also shown positive effects on parent's depression, anxiety, and coping mechanisms (Iadarola et al., 2018). While the result of treatment seems to be beneficial to family members, this may not be the case for all. Low-income families are more likely to experience greater depressive symptoms throughout the process of applying for and receiving services (Orsmond et al., 2007), and more likely to encounter barriers in obtaining services, such

as a lack of information, work scheduling conflicts, and transportation issues (Pickard & Ingersoll, 2018).

The Present Study

Given the experience of obtaining an ASD diagnosis for one's child, the support needed for all family members cannot be understated. Treatment plans are best created and implemented when the patient and family as a whole are considered, as this in-depth knowledge of patients and families allows for multifaceted treatments promoting their health, development, and wellbeing. While systems and policies are in place to ensure family's needs are met, there are still barriers in accessing them. This speaks to the biopsychosocial model as socio-environmental factors are involved. As such, the purpose of this collective case study was to investigate the experiences of parents in the Canadian province of Quebec in obtaining a diagnosis and services for their child with ASD, and identify what aspects were beneficial to them, as well as what challenges they experienced. The research questions were three-fold: (1) what was the parent's experience obtaining a diagnosis for their child with ASD?; (2) what was the parent's experience obtaining services for their child with ASD?; and, (3) what was the parent's experience with schooling for their child with ASD? The qualitative nature of this study adds to the extant literature by addressing multiple milestones in the child's development, each of which are accompanied by unique challenges, and allows for mothers' voices to be heard and their stories to be told.

Method

Participants

After receiving ethical clearance from the University's Research Office, a recruitment period was initiated (see procedure). Families with at least one child with ASD and one TD child were eligible to participate; six families volunteered. In families with two children with an ASD diagnosis, both were considered when mothers described their symptomology and experiences. See Table 1 for parental demographics.

Parent 1 is a single mother of four; the two eldest, ages 7 and 8, are TD and the two youngest daughters ages 3 and 4 were diagnosed with ASD. Parent 2 is a working mother of an 11-year-old son diagnosed with Pervasive Development Disorder Not Otherwise Specified (PDD-NOS) at the age of 2, and a 9-year-old TD daughter; both attend the same school. Parent 3 is a stay-at-home mother of four; two TD daughters, ages 7 and 12, and twin 10-year-old boys both on the spectrum, all attending the same school. The boys were both diagnosed at the age of 3. Parent 4 is a working mother of a 6-year-old TD daughter and a 4-year-old son diagnosed with ASD and language impairment at the age of 3. Parent 5 is a stay-at-home mother of three children; a 12-year-old son and a 10-year-old daughter both diagnosed with ASD at the age of 4 and 2 respectively, and a 7-year-old TD daughter. Parent 6 is a working mother of a 9-year-old TD daughter and an 8-year-old son with ASD, diagnosed at the age of 7; both attend the same school.

Public Assistance

Some families received public assistance from two major community centres run by the Quebec provincial government: (1) Local Community Service Centres (CLSC), and (2) a readaptation centre. CLSCs offer routine health, social, preventative, medical, rehabilitation, reintegration services, and public health activities. The readaptation centre, geared towards individuals with ASD, PDD-NOS, and intellectual disabilities, offers residential and community integration, rehabilitation, and habilitation services.

Procedure

First, we initiated purposive sampling recruitment (Saladaña, 2016) through word-of-mouth and online parent support groups. The first author contacted individuals within the community who were in a position to refer participants, as well as posting a flyer advertising the study on various online support groups. All parents made initial contact with the first author, who set up a time to review the study's goals, procedure, and answer any questions over the phone. After agreeing to participate, the first author and mother set up a time for a home visit. Mothers provided written consent and then completed a demographic questionnaire and a semi-structured interview, which was later transcribed.

Measures

Demographic Questionnaire. Mothers completed a brief demographic questionnaire regarding their own and family environment (e.g., age, education), child(ren) with ASD and their TD child(ren), such as age, birth order, gender, and services received.

Open-ended Interview. Mothers were interviewed by the first author regarding their child's symptomology, diagnosis, school experience, and use of support groups. The interview occurred within the context of a larger study focusing on the sibling relationship. The interview was semi-structured, consisting of open-ended questions, with prompts if needed (see Appendix A). All interviews were conducted in the family home and lasted approximately one hour.

Thematic Coding

The transcribed interviews were analyzed in stages. After the interviews were typed, parents engaged in first level member checking by reading the transcript to ensure their messages reflected what they wanted to say. Once mothers approved the content, the authors read the interviews searching for patterns before generating codes (Braun & Clarke, 2006). The authors then engaged in theory triangulation by identifying and categorizing codes independently. Statements were analyzed for meaning and a label was attached, representing the phenomenon of interest (King, 2004). This was done to integrate various amounts of data into etic themes (Bratlinger et al., 2005). The themes created were data driven, meaning there were no pre-existing

categories to fit codes into (Braun & Clarke, 2006). Themes and subthemes were reviewed and discrepancies between the coders were discussed and reconciled (Saldaña, 2016).

Several methods were used to ensure trustworthiness of data (Hays & Singh, 2012). As mentioned, member checking was used to ensure confirmability of the typed transcripts. Additionally, simultaneous data collection and analysis occurred, as interviews were typed and read by the authors before the interview process was completed for all participants. Investigator triangulation of data analysis also enhanced the credibility of the results.

Results

Three major themes emerged in parent interviews (see Figure 1): (1) early signs and the diagnostic and intervention experience, (2) school experience, and (3) the need for and lack of support.

Early Signs of ASD and the Diagnostic and Intervention Experience

As ASD symptoms and severity vary, parents were asked to describe their child's tendencies and behaviours. Parent 2 described the first signs that something might be wrong in her son's development:

The repetitive behaviours... because [he] used to be very infatuated with hoses, vacuums, wires...anything along those lines. Those were all signs for us obviously. The eye contact, or lack thereof... That was the other sign, the lack of hugging. We weren't allowed to touch him or anything.

Similarly, Parent 3 mentioned "We know something was up...we couldn't put our finger on it because we didn't know what *it* was", but the parents noticed rigidity, sensory issues, and a lack of affection. Other parents mentioned delayed and poor communication, as well as poor emotional regulation, self-help and adaptive skills, and repetitive behaviours. All children had obtained an official diagnosis and were currently receiving support at the time of the study.

The Diagnostic Experience

Obtaining an official diagnosis was difficult for some families. Firstly, for most families the wait to be assessed in the public system was not done in a timely manner, thus leading them to go through private services.

Parent 4 experienced difficulty with her pediatrician, as concerns that her son was nonverbal at 18 months were "Brushed off...he's like 'oh you young parents, you think you know it all'". Parent 6 described a similar encounter with her pediatrician, who also did not see cause for

concern at age three because “He’s so young...maybe a little speech impediment but give it a chance he’s still young”. Moreover, because her son made direct eye contact with the doctor, he ruled out ASD. When Parent 4’s son was diagnosed, she felt as though she received a diagnosis “You know nothing about... They throw you into a river and they say go swim with these sharks...”.

Parent 3 noticed in preschool that her two boys were struggling and not “Getting into it like the others”. Her boys did not interact with the other children in the daycare and experienced difficulty adapting to the new routine and surroundings. The daycare “Didn’t seem like they wanted to help, and we were kicked out essentially”. Nevertheless, several parents seemed to take a proactive stance and acquired the necessary therapies for their child(ren).

The Intervention Experience

A variety of interventions were sought by parents, including Applied Behaviour Analysis, speech therapy, occupational therapy, social skills training, and food therapy (i.e., repeated presentation of a certain food and gradually increasing the amount to overcome smell and taste sensitivities; Williams & Seiverling, 2014). Parent 4 began the intervention process before receiving an official ASD diagnosis, as she did not want to wait given the slowness of the diagnosis process. Her son received speech therapy and occupational therapy before he was diagnosed, followed immediately by ABA therapy. She further described how her son’s communication improved with ABA and speech therapy: “...Now we won’t give him water unless he says, ‘I want water’ or ‘can I have water?’... Because, initially, he would only point”. Similarly, Parent 5 explained her son began speaking in full sentences at age nine, after years of various interventions. His communicative improvements have allowed him to develop a friendship with his TD younger sister over the last few years, which their mother is very happy about.

Although the interventions received were deemed helpful, going through the public system was often problematic. Parent 2 stated:

We were doing it privately; we weren’t being picked up by the system obviously because it takes a really long time... yes, it was a fortune [private services], but it was the best money that was spent because it really helped him... repetitive behaviours have stopped for the most part, and eye contact is there, affection is there.

This sentiment was similarly expressed by Parent 4:

We decided to do everything privately. So, we skipped a lot of the waiting lists, but at a cost... And [the system’s] not doing anything to help with that. Like, the local CLSC [public health clinic], I have a social worker, never met her... So, what do I do in the meantime? I let him do nothing? No, I can’t. But we had to sell a property to help him.

Parent 3, who also went privately “Because our system sucks”, still applied for government funded services: “I basically went from the psychologist to the CLSC... but there was a ball dropped somewhere... by the time they called us he was six...and at six they don’t give [services] to you anymore”. Nevertheless, Parent 3 mentioned that “He’s come a long way” especially in his rigidity behaviours. As a young child, she remembered “He had to have the blue cup, sit in a certain spot, have a certain bowl...”, but they worked very hard to “Pull him out of that”. It appears that parents dissatisfied with the public system found an alternative solution so their child could receive the services they needed, but at a personal and financial cost.

The Experience of Attending a General Education School

Due to the range of ages and symptom severity of children with ASD, their schooling varied; three children attended child care (Families 1 and 4), four attended public school (Families 2, 3, and 6), and two went to a special needs school, which offers various supports that might not be available in general education schools (Family 5). For the children still in child care, mothers were not specifically asked about their experience with school. Parents 2, 3, and 6 all said their children have made friends at school and are good at certain subjects, while they struggle in others. Children 3 and 6 were put on an IEP (Individualized Education Plan), and their parents spoke quite negatively about their sons’ and their own experience with the school. For example, Parent 3 sees her son as passive in his education and unmotivated to try:

...He’ll retain only a small percentage of what’s being told to him and he doesn’t understand... he can’t be left alone. He really needs someone next to him to help him. He doesn’t work at all... he doesn’t feel motivated to go to school.

Parent 6 articulated similar sentiments when she said, “He refuses to do work. His last report card in French, it wasn’t like the mercy 60%, it was blank”. She continued to explain that her son is becoming aware of the differences between himself and his peers, as he is “Not at the same point as everyone”, which embarrasses him. As such, he will be attending a special needs school in the following school year.

While the children with ASD attending public schools were said to have made friends, they still struggle socially. Parent 3 explained her son “... Has a group of friends that they play manhunt or tag... And the kids he plays with kind of get him. But there are kids who go after his emotions”. For example,

In fall [son with ASD] and his friends were just like collecting leaves, and this kid with his friend were taking the leaves and throwing them around... And [son with ASD] said, told him, ‘please stop’ and he had apparently told him many times ‘please stop, you need to stop’ and this kid thinks it funny, you know...and he does it again and [son with ASD] just blew up, went after the kid...

Parent 6 explained she sees her son as stigmatized, “Kids his age... they’re not necessarily mean, they don’t do it intentionally... but they say things and it just hurts his feelings...”. Her son is in a difficult situation, as “He’s able to develop relationships... but still there’s something lacking. He’s misunderstood, he doesn’t get the social cues”. Parent 5, whose two children with ASD are severely disabled, explained her daughter “Loves to be tickled. It’s her only way to play with people because she can’t really talk, so it’s tickle, tickle, tickle”.

The lack of resources within the education system was also mentioned by mothers. Parent 6 explained the classroom aide is often unavailable or cannot stay with her son for a long period of time as she tends to many students. Parent 3 voiced similar criticisms and dissatisfaction, as the school was not offering enough support or assistance to her son:

...We have to work on it, but we can’t always pinpoint what *that* is. So, we look to the professionals at school but they’re not giving you that. The principal is really quick to send him home for anything, when he should be working with his aide in a resource room on his tools that we had been doing with our [re-adaptation centre] psychoeducator.

Moreover, the psychoeducator (i.e., a qualified health educator or professional that evaluates various issues and proposes solutions that are specific to the child) provided family 3 with many tools and recommendations. Yet, this professional has also experienced resistance from the school in implementing her ideas:

Consistency is huge, right, for anybody. Especially for a young boy with special needs. So, working with [re-adaptation centre] all year, [the psychoeducator] is like ‘I never experienced this much resistance from a school trying to get in there and help them... why aren’t you guys taking free help. Professional free help?’

It seems parents and professionals encountered obstacles while trying to provide for children’s differing needs in the school setting. Academic and social issues were encountered by families, such as bullying, stigmatizing, a lack of school resources, and barriers in implementing proper supports. Such problems are perhaps amplified for children with ASD in primary and secondary school.

One parent did speak positively of their school experience. Parent 2 explained the logic behind putting her son “Into mainstream [public] elementary purposefully... in the hopes that if it didn’t work out, we could go to a smaller school, but if we put him into a smaller school, you’re leaving less options”. She is quite happy with her decision, as her son has made good friends, follows a regular curriculum with small adaptations, and does fairly well academically.

The Need for and Lack of Support.

While no families were members of formal support groups, some had considered joining one. Parent 3 said: "...We looked into it, and you know, when things are going well that's when you don't, but that's really when you should. But it's just hectic". Similarly, Parent 5 stated: [Focal child] never had any intervention on her to deal with anything. There's been times where she probably needed it and it just kind of...didn't happen". Parent 4 expressed her strong belief in and need for support:

The beginning is very hard because you're getting a diagnosis that you know nothing about. And, I find if you don't have the support there's no way you can get through it. Because, when we got our diagnosis all my friends were like, 'it'll be okay' and I find that the 'it'll be okay', that's coming from someone who doesn't know what you're going through means nothing. If you don't live it, you don't know it. Just the fact that you're telling me this is what *I did* with my son, I know you went through it and I can trust you.

Parent 4 does have an informal support group, where families "Get together every once in a while. So, we rent out a gym and we all bring our kids with special needs and their siblings, and they just play, we share stories. I've learnt a lot from that". One expectation of these informal support groups is that as the TD siblings get older, Parent 4 hopes they will be able to turn to each other for support, advice, and companionship. This expectation is based on the common experiences that these families are experiencing with a child (or two) with ASD.

Discussion

The purpose of this qualitative study was to explore the maternal experience of obtaining an ASD diagnosis for their child(ren), the availability of services, and experiences with schooling. Many mothers expressed discontent with the public services received, or not received in some cases, as well as with the education system.

What Mothers Thought of The Public Healthcare System

In response to research questions one and two, after waiting several months and not getting a response from the public system, most families chose to pursue private assessments and support for their child. Mothers mentioned it was taking too long to hear back about receiving public services or were told that they would have to wait over a year to receive assistance. This finding is in line with a Quebec study conducted by Rivard et al. (2015), where parents ranked accessibility as one of the most important quality determinants of public services, but also as the least

implemented. The long wait time experienced by the mothers in the current study is also a common theme reflected in previous findings (i.e., Crane et al., 2015; Mansell & Morris, 2004; Osborne & Reed, 2008; Potter, 2016), and is linked to parental stress (Rivard et al., 2015). It is not surprising that parents wished for a quicker and easier diagnostic and intervention process given their concerns. The level of difficulty experienced in obtaining support for their child may speak to the low level of employment within the current sample. A comprehensive review of employment rates in families where a child has a disability reported that families of children with ASD experience more negative work-related events than families of TD children or children with other disabilities (Maich et al., 2019), which may be related to the level of professional support. Our findings suggest that at the time of diagnosis, pediatricians and other professionals explore the different intervention options with parents, and offer referrals for services. In addition, professionals can further support parents during the waiting period by focusing on their ability to nurture and care for their child through their existing strengths, knowledge, and character. As informal support has a positive effect on parental stress (Halstead et al., 2018), it can and should be provided before formal support is received.

The Drawbacks of Sending a Child with ASD to a Mainstream School

A similar complaint related to the lack of school resources was expressed by mothers whose children with ASD attended public school, in response to research question three. Mothers mentioned their child rarely saw or had a substantial amount of time with their classroom aide. This is in support of Brown et al. (2012), where Canadian parents described their child's needs as being unmet at school, as well as a lack of consistency and follow through from the administration, which was expressed by mothers in this study, as well. As school-age children are no longer eligible for early intervention services in the province (Quebec), such discontinuity may be more likely to occur. However, as highlighted here and in previous literature, it is extremely important for the development and prognosis of children with ASD that rules, responses, and expectations be consistent across different contexts (Brown et al., 2012; Rivard et al., 2015). Unfortunately, as documented in previous studies, some mothers in the current sample experienced pushback from the school when trying to implement ideas that had previously helped their child succeed academically and socially (Brown et al., 2012; Mansell & Morris, 2004; Osborne & Reed, 2008). Apparently, parents and professionals were willing and eager to provide strategies to help children with ASD but faced barriers in the actual implementation in the school setting. This speaks to the need for better coordination and communication between early intervention services and school personnel. Moreover, it is critical that schoolteachers, administrators, and resource teams be knowledgeable about ASD and have the proper supports in place to ensure each student can excel.

While parents indicated that interventions were effective in the current sample and in previous literature (i.e., Estes et al., 2019), the lack of continuity may partially explain some of the difficulties experienced by children with ASD at school. Mothers reported their children with ASD had become passive, unmotivated, and anxious when it comes to school and the associated social and academic expectations. Mothers felt their children had also become aware of the differences between themselves and their peers, which may further discourage them academically and socially.

This perception is supported by Ashburn et al. (2010) in that teachers described their students with ASD as having low adaptive functioning, because they were anxious, depressed, withdrawn, and socially and academically delayed. Moreover, students were considered inattentive, oppositional, aggressive, and withdrawn, which can further explain the poor academic achievement and social problems reported by mothers in the current study.

What Can Change to Help Families

Such findings speak to the need for additional parental and child support. Through informal support children have the opportunity to meet and interact with other children with various disabilities, which may encourage their social development and help alleviate their feelings of social isolation experienced at school. Formal support has also shown to be helpful for parents of children with ASD. For instance, practicing mindfulness techniques helped to reduce parental anxiety, depression, insomnia, and enhance overall wellbeing, self-compassion, personal growth (Dyken et al., 2014). However, given the difficulties described, social support can also be a significant contributor to parental wellbeing. Several studies have noted that informal social support was a protective factor against stress and can be more beneficial than professional support for parents of children with disabilities (Halstead et al., 2018). While one family had an informal support network consisting of other families whose children had developmental or physical disabilities, some families mentioned they knew it would be helpful but did not seek out such a group. This again speaks to the relevance of family systems theory (Cridland et al., 2014). If parents feel supported by professionals and their community, this has the potential to reduce stress and other negative emotions, which impacts the well-being of the other family members in the home.

Additionally, there is a need for reform within the current education system as certain children seem to fall through the cracks. As argued by advocates of the biopsychosocial model of disabilities (Chown & Beardon, 2017), it is not enough to label the disorder and treat the individual without considering the bidirectional interaction these individuals have with other members of society. The obstacles imposed by schools should be replaced with a willingness to implement whatever strategies and plans are necessary to allow for the success of children with ASD or other developmental disabilities. Given the difficulties experienced by parents and children alike, it stands to reason that many parents voiced the need for more responsive formal and informal supports.

Limitations and Conclusions

Although the study produced rich findings, we note some limitations. The small and homogenous sample size of six mothers is problematic, as findings may not generalize to other families. We also did not receive input from fathers, who may have a different perception or suggestions. Additionally, the timeframe of the study did not allow for longitudinal information for families whose children were still in child care and had not yet encountered formal schooling.

Nevertheless, this study allowed mothers to voice their experiences, concerns, and frustrations with the process of obtaining a diagnosis and following into their children's primary school years. The findings highlight the need for professionals to take parental concerns for their child's atypical development seriously. Moreover, parental support should be provided at the time of diagnosis, but continuously afterwards and in a timely manner. Parents deserve to have easily available and reachable professionals, as well as advice and support in terms of interventions and their accessibility. Additionally, to relieve some parental stress when their child with ASD transitions to primary school, systems must be in place to promote success for the child and the family. This starts with open communication between intervention providers and school administrators with regards to effective strategies and their ongoing implementation. Essentially, the use of assisted teaching strategies and techniques that have previously proven helpful to the child with ASD should be easily transferred to their new school. The conclusions and implications underlined in the current study should not be disregarded, as they speak to the current issues faced by families within our society.

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Table 1
Parental Demographic Information

| | Mother | Father |
|------------------------------|---------------|---------------|
| Age range | 33 – 45 | 37 – 45 |
| Mean (SD) | 38.16 (4.44) | 42.33 (3.20) |
| Employed: unemployed | 3:3 | 5:0 |
| Mean number of children (SD) | | 2.83 (0.98) |
| Religious affiliation | | |
| Christian | 4 | 4 |
| Jewish | 1 | 1 |
| Non-observant | 1 | 1 |
| Level of education* | | |
| High school | 1 | 1 |
| College | 1 | 1 |
| University | 3 | 3 |
| Annual income | | |
| < 20, 000 | | 1 |
| 20, 000 – 35, 000 | | 0 |
| 35, 000 – 50, 000 | | 1 |
| 50, 000 – 75, 000 | | 1 |
| > 75, 000 | | 3 |
| Married: single | 5:1 | 5:0 |

* One mother did not provide her level of education

Appendix A

- 1) Can you describe [name of child(ren)] symptomology?
- 2) What made you have [name of child(ren)] assessed?
- 3) Can you tell me about the diagnosis process?
- 4) How are [name of child(ren)] symptoms or behaviours today?
- 5) How is [name of child(ren)] doing at school?
- 6) Do you or [name of TD child(ren)] belong to any support groups or sibling groups?