

“Managing the Wait”: Parents’ Experiences in Accessing Diagnostic and Treatment Services for Children and Adolescents Diagnosed With Autism Spectrum Disorder

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ABSTRACT

BACKGROUND: Parents of children and adolescents diagnosed with autism spectrum disorder (ASD) report delays in accessing timely diagnostic and treatment services for their children. Research has generally focused on parents' experiences in caring for a child diagnosed with ASD. This study describes the process of how parents access ASD services for their children and adolescents.

METHOD: This study used a qualitative research design that was informed by grounded theory methodology. We used constant comparative analysis to develop a process model and a core concept.

RESULTS: Seventeen parents of children and adolescents diagnosed with ASD were interviewed. Our process model included 3 main phases: Watchful waiting (noticing suspected behaviors, and searching for assessment and diagnosis); Informed waiting (receiving the diagnosis, facing challenges in accessing treatment services, and realizing the impact of an ASD diagnosis); and Contemplative waiting (pondering the future, reflecting on the past, and making recommendations). “Managing the Wait” was identified as the core category central to parents' experience of this process. This process was found to be impacted by socioeconomic status, parents' skills and capacity to advocate on their child's behalf, and severity of their child's ASD.

CONCLUSIONS: Our findings illustrate the many barriers families face during their journey in accessing ASD services. Our results illustrate the need to address wait times for services, and provide education and support services for parents as a means of improving their self-advocacy skills, especially for parents of children and adolescents with severe disability.

KEYWORDS: Access, autism spectrum disorder, children, health care services, qualitative, socioeconomic status

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Background

Autism spectrum disorder (ASD) raises a number of unique challenges in terms of clients accessing treatment and support services. It is a complicated condition that requires a variety of services that change over time. Often services are provided through a range of government departments and providers that frequently require integration and collaboration between health care, education, employment, and social support sectors.^{1,2} There are recently reported significant increases in prevalence and a global prevalence rate of 1 in 160 children, with many countries having higher rates; as a result, there are additional demands for ASD services, which were already identified as being inadequate in most countries.¹

Early identification of ASD has been deemed a priority because the best chance for improving symptoms occurs through early and intensive interventions.^{1,3-5} Parents play a key role in facilitating any access to services because most clients are minors when they are diagnosed. A definitive ASD diagnosis is often a prerequisite for children to access publicly funded services⁶; yet, obtaining a diagnosis in itself can be stressful, frustrating, and

time-consuming for many families.⁷⁻¹¹ Confirming a diagnosis can involve visits to numerous health care professionals to rule out other possible conditions.¹² Although the recommended maximum wait time between initial referral and ASD diagnosis is 5 months,¹³ the average time between parents' initial concerns with their child's development and diagnosis is generally between 2 and 4 years.^{14,15} Once diagnosed, families then have to arrange for services across a wide range of providers and settings, including those in the education system. Wait times in accessing these types of services is a key issue faced by families.¹⁶ As clients get older, there can also be abrupt changes in services as children pass the age requirements of specific programs or require different types of services more appropriate for their stage of life and development.

DePape and Lindsay¹⁷ explored parents' experiences in caring for a child with ASD across various countries and 6 main areas of parental experiences were identified: prediagnosis, diagnosis, family life adjustment, navigating the system, parental empowerment, and moving forward; reportedly, there were negative implications for parents during all of these stages.



Similarly, a metasynthesis of qualitative studies explored parenting a child younger than 12 years of age diagnosed with autism and found that parents faced many challenges that changed over time.¹⁸ The lived experience of parents who had a child with autism was also investigated and “Living in a world of our own” emerged as the essence of that experience wherein parents described living in a world of isolation.¹⁹

Another key aspect in accessing services is the financial impact. Raising a child with ASD was found to be associated with more profound employment and financial burdens for parents compared with children with other types of disabilities and that more than half of families of a child with ASD indicated their employment had been disrupted by autism-related child care difficulties in the past year.²⁰ In Canada, many of the health and educational services needed by clients with ASD are publicly insured, so that there should be no actual financial barriers in accessing these services. Yet due to lengthy delays, those who have the financial means may choose to look for private services as a means of acquiring quicker access paid out-of-pocket.²¹ As a result, this situation raises the possibility of a 2-tiered health care system that is based on a family’s socio-economic status (SES). In fact, evidence has shown that parents who report higher income and education levels express increased satisfaction with the diagnostic process and report fewer barriers.^{3,11,12,22,23} Economic hardship has been reported by families who make the choice to pay for private services who cannot really afford to do so.¹⁶ Other financial challenges for families include restrictive insurance coverage, the need to take time off from work to care for their child, and lack of available transportation to take children to appointments.²⁴ Yet the exact impact that SES has on the overall process of accessing services is unclear. Research has shown that parents who identify as a visible minority, have lower economic status, and live in a rural setting receive a delayed ASD diagnosis for their children.^{23,25,26} However, other researchers found that neighborhood income did not affect the age of ASD diagnosis for children.²⁷

Our study explores parents’ experiences of accessing diagnostic and treatment services over the life course of ASD in one Canadian province. We also explore the extent to which a family’s self-described SES affected their access to services. There are still important gaps in our knowledge about experiences families affected by ASD have in accessing diagnostic and treatment services. It is our hope that this study will expand the conceptual understanding of those experiences as well as to provide direction on how to improve services for clients and families affected by ASD.

Method

Design and data collection

We used a qualitative research design guided by grounded theory methodology.²⁸⁻³¹ The assumptions on which grounded theory is based is symbolic interactionism wherein human

behavior and the roles that individuals play are negotiated and renegotiated in a process of interactions that change over time that is the most appropriate approach when looking at psychosocial processes.³² Grounded theory is built on compared concepts and constant comparison through which similar data are grouped and conceptually labeled during open coding.²⁸⁻³¹ Afterward, concepts are categorized and linked and organized by relationship in a process called axial coding. Finally, when conditions and dimensions are developed through an interpretive process called selective coding, a theory emerges.²⁸⁻³¹ Grounded theory methodology was seen as particularly useful in this study, in which the focus of inquiry is to discover the strategies parents use over time in dealing with accessing diagnostic and treatment services for their children and adolescents affected by ASD.

We used purposive sampling, selecting participants who could provide data relevant to our study aims. Participants were parents of children diagnosed with ASD who had experience accessing ASD diagnostic and treatment services for their children in the province of Newfoundland and Labrador (NL). Two research assistants under the supervision of the third author conducted interviews as part of a wider needs assessment for autism services for the provincial Autism Society.³³ The interviewers were both a male and a female in their early 20s, who often conducted the interviews together. Neither of them had a child with ASD. Our analysis of the data did not reveal any significant issues relating to the gap in experience between the interviewers and the parents who were interviewed. Parents were invited to participate in a semi-structured interview. Each consenting participant provided written informed consent prior to being interviewed. Parents were asked questions to explore their overall experiences in accessing diagnostic and treatment services for their children through the life course of their condition.

Interviews began with parents describing when they first noticed suspected ASD behaviors and their experience in accessing diagnostic and treatment services for their children. As the interviews continued, more focused questions were asked (i.e., what, if any, impact the ASD diagnosis had on their families and/or financial situations). Finally, parents were asked to reflect on their overall experiences and offer suggestions to improve services for other parents. Interviews were audio-recorded and transcribed verbatim. Confidentiality was assured by removing all identifiers from the interviews during transcription and using numeric codes to identify participants. Ethics approval was granted by the Memorial University of Newfoundland’s Human Investigation Committee.

Data management and analysis

We conducted our analysis in 3 stages: first, coding interview transcripts and establishing preliminary themes through frequent comparisons; second, recoding the data using the preliminary

Table 1. Demographic information of children/adolescents.

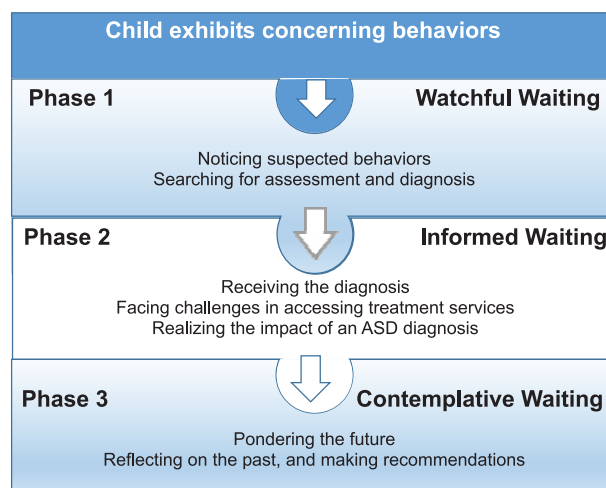
AGE CATEGORY	N	SEX OF CHILD	
		MALE	FEMALE
Children (aged 1-10 years)	8	7	1
Early adolescence (aged 11-14 years)	4	3	1
Middle adolescence (aged 15-17 years)	1	1	0
Late adolescence (aged 18-21 years)	4	4	0
Total	17	15	2

themes and identifying the ones used more frequently; and third, organizing resulting themes into overarching categories; finally, we identified a core category to which all the categories were related that best fit the pattern of behaviors parents used that captured what was happening within the data.²⁸⁻³¹ At each stage of analysis, the first author conducted the initial coding followed by the second and third authors who reviewed the coding, queried interpretations, and challenged assumptions. Trustworthiness was achieved through peer review and involvement of the 3 authors having different areas of expertise throughout the analysis. The 3 authors have extensive experience in analyzing qualitative data. The core category and ensuing categories are presented in the findings with quotes to illustrate each phase of the process.

Results

Seventeen parents that included mothers ($n=13$) and fathers ($n=4$) of 17 children and adolescents with ASD aged 3 to 19 years ($M=10.5$ years, $SD=5.8$) participated in a semi-structured interview lasting approximately 1 hour. All children and adolescents were reported by parents as being verbal and diagnoses of ASD were confirmed through parent reports (see Table 1 for further demographic information).

We recognized waiting as a key feature in parents' experiences and found that managing the wait included 3 main phases over the life course of the condition. The process began as parents initially waited to find out whether or not concerning behaviors they were noticing in their children were permanent or transient. They were subsequently required to wait in the public health system for appointments with health care professionals, usually with a family doctor and subsequently a pediatrician to have their child assessed and diagnosed. They would then face additional waiting to access intervention and treatment services for their children with other health professionals including speech therapists, occupational therapists, and physiotherapists. As they received information about ASD, they began to realize the impact this condition might have on the future that left them once again waiting to see what would happen, looking forward to what services their children might need in the future. Finally, they would reflect on their experiences when their child was first diagnosed, what

**Figure 1.** Process model of "Managing the Wait."

they found lacking in the system, and make recommendations that would hopefully improve other parents' experiences and better prepare them in managing the wait. "Managing the wait" was identified as the core strategy parents used throughout the entire process (Figure 1).

Watchful waiting

In the first phase of "Watchful waiting," the definition of waiting can be described as, "remaining stationary in readiness or expectation."³⁴ In this phase, parents, family members, or other caregivers were noticing children displaying suspected ASD behaviors. Some behaviors seemed easily recognized yet others appeared to be less pronounced. Parents were watching and waiting to see whether their children's problematic behaviors would resolve or persist. Watchful waiting included 2 sub-phases: noticing suspected behaviors and searching for assessment and diagnosis.

Noticing suspected behaviors. In this first subphase, parents and other caregivers began noticing suspected ASD behaviors in children such as an inability to make eye contact, difficulties in social situations, delayed speech, problems with sleeping and eating, struggles with fine and gross motor activities, repetitive behaviors, and overreactions to environmental stimuli such as scents, noises, and crowded places. Some behaviors were noted in infancy. "He didn't have good eye contact . . . I wasn't looking for it but noticed it." Others noticed it during the toddler years:

He was different probably just before he turned 3 years old like he'd get really latched on to things like really concentrate and just couldn't break that boredom cycle and had these really strange kind of hand gestures that he would be doing all the time and there were the sounds he'd make—odd noises at certain times and you know they might last for 30 minutes . . . he didn't interact socially.

When children became school age, others brought their attention to certain behaviors.

“His kindergarten teacher recognized it and she said that [child’s name] is really withdrawn. He doesn’t like me to touch him. He doesn’t play with other kids.” A sudden regression in behaviors caused concern:

I was thinking that he was deaf because he had been speaking and then all of a sudden he lost what speech he had and he wouldn’t come when you sang out to him, he wouldn’t pay attention to you anymore. He just totally ignored everything.

Parents spoke about experiencing a “gut feeling” as concerns became more evident:

This gut feeling that was always there that we knew there was something not right . . . there was something wrong and you couldn’t help it or put your finger on it . . . He just didn’t like to be in public noisy places. He was a difficult sleeper . . . constant motion, movement was a big thing for him.

Parents were recognizing suspected signs and symptoms of ASD in their children leading them to search for assessment and diagnosis, subsequently confronting challenges within the publicly funded health care system.

Searching for assessment and diagnosis. A speech language pathologist was often one of the first health care workers to recognize signs of ASD. They would often recommend further assessment that prolonged the waiting:

[We] waited eight months to get into speech . . . the speech language pathologist was the first one that even hinted that there could be something. She suggested that we go to get tested for autism . . . it was 19 months [on the wait list] from the time we started; [it] was 36 months when he got his diagnosis.

Parents spoke about how some health care providers had advised them to wait to see what happens in their children’s developmental progress before accessing diagnostic services that resulted in delays. “We saw our family physician and it was just kind of, ‘no—wait and see, wait and see.’” The prolonged time it took for parents to get a diagnosis for their children was apparent:

We noticed it when he was around 19 months . . . We got him referred when he was around 24 months . . . It took about 8 months to get in for testing. We went three times for testing . . . He was almost four years old when he got diagnosed.

Hoping to gain timely access to assessment and diagnostic services, some parents looked for service provision in other parts, or outside the province. “I just used some of my health care connections and I saw a doctor in another part of the province who was quite comfortable making an autism diagnosis.” Often the waiting process was further complicated by inaccurate or missed diagnoses:

He wasn’t meeting his milestones as a baby . . . they always said, “He’s just a very quiet baby and when he’s two years old he’ll be

perfect just give him some time. He’s a bit slower.” So I never thought anything of it . . . Then the pediatrician wanted to check for muscular dystrophy and cerebral palsy . . . Then we started all these very intrusive diagnostic tests . . . muscular dystrophy was ruled out, cerebral palsy was ruled out . . . saw the top pediatric neurologist in Canada and we did genetic counselling . . . global delay . . . Now he’s diagnosed with autism.

Once an ASD diagnosis was received, parents began to understand what the diagnosis meant that led them into the second phase of the process.

Informed waiting

In “informed waiting,” the concept of waiting can be described as “looking forward expectantly.”³⁴ Parents were starting to become informed about ASD and what it meant with a desire to access timely and appropriate health services for their children. This second phase included 3 subphases: receiving the diagnosis, facing challenges in accessing services, and realizing the impact of an ASD diagnosis.

Receiving the diagnosis. Parents spoke about having varied reactions at the time their children received the diagnosis that included feelings of shock, disbelief, confusion, anger, sadness, worry, denial, and guilt. They also talked about how difficult it was to accept the diagnosis:

At the beginning, I didn’t believe it because my perception of autism was a little kid in the corner banging his head and that’s not what [my son] was. [My son] was like really, really smart but he didn’t socialize . . . [The pediatrician] said, “Have you seen the movie the Rain Man?” and I said, “Yeah.” I said, “Are you telling me [my son] is autistic?” And he said, “Yeah.” He said, “He’s definitely on the spectrum . . .” I got three different opinions because I just didn’t believe it. I knew he was different but didn’t think it was something that would be labeled.

Other parents expressed how they had expected it and weren’t really surprised their child had received a diagnosis of ASD:

I wasn’t surprised by the diagnosis. I’ve done a little bit of research while we were waiting for everything to happen and when it came back I was like that seems smack on to me . . . it explained the situation.

Still, others were shocked:

You’re so shocked when you hear it that you don’t even know what to ask—like you don’t know what to say other than, “Is this terminal? Is this something that’s going to kill him? . . .” I kept thinking afterwards like this must be pretty severe if they’ve already got a society and it’s right here pretty much attached to the [children’s hospital] . . . like this must be really bad . . .

Feelings of disbelief, sadness, concern, and guilt were common reactions to receiving the diagnosis:

Within like 30 minutes he [pediatrician] came out and he said, “You know, sorry your son has autism.” After being given the diagnosis, I was like a mess for two days. I couldn’t even talk. How did it happen? Why did it happen? Am I responsible for this?

Parents who had been expecting the diagnosis expressed relief because they believed support for their children would soon be provided. “We knew he was autistic long before he had a diagnosis. We only got the diagnosis so he could get the services.” Others felt angry and bitter toward their health care providers indicating they had shown lack of empathy and indifference when the diagnosis was provided. The economic and financial impacts of ASD were also becoming apparent. At the time, Applied Behavior Analysis [ABA] therapy was not publicly insured.

Basically, you had to pay for your own therapist . . . \$35,000 to \$60,000 a year depending on the amount of hours . . . it blew us away! I just couldn’t believe it. I was so angry with the doctors . . . I was very angry. At one point he had to tell me to calm down. It wasn’t a nice conversation. My wife was crying obviously. It’s very traumatic!

Once their children had been provided a confirmed diagnosis of ASD, parents were expecting timely access to therapies and supports for their children because they understood early intervention was important yet they were challenged once again by wait times.

Facing challenges in accessing treatment services. As parents attempted to gain access to treatment services and therapies for their children, wait times remained a concern:

When you hear the word autism you’re introduced to the fact there’s a 12 to 18 month wait. So that’s 12 to 18 months wasted. Then OT [occupational therapy] took us two years to get in, speech took us six months. It’s unacceptable from my perspective. That’s precious time wasted . . . ABA we were put on a wait list—it was a good six or seven months . . . The wait list was really, really long for speech [therapy] . . . We applied for [autism service dog] . . . it took three years to get him.

Parents were starting to weigh the pros and cons of deciding to wait for publicly funded services or facing the financial burdens associated with paying for private services on their own. “The bad thing about [private service provider] is it’s very expensive and it’s not covered under [public insurance]. I’m paying \$500 a term for him to go there whereas [public service] is free.” For those who had the financial means to pay for private services, they would reflect on the benefits of that:

The thing with private services is that it was happening regularly and when we had private speech we knew who was coming through the door. There was a relationship . . . When you’re paying for this out of pocket for the private system, there is a contract between you and them . . . you feel more as a consumer of a service when it’s private.

Parents recognized the divide in service provision between health care and education:

You’ve got two systems that are not working together . . . ABA therapists are not allowed in the school . . . You’ve got a healthcare system that doesn’t communicate with the education system and you’ve got this disconnect.

Parents who had attempted to obtain financial supports from government agencies were being challenged by those bureaucracies:

We applied for the special child welfare allowance. We filled it out twice and never heard about it. It’s invasive and weird and difficult to fill out. They lost the first one. We never heard back from the second one.

Demands associated with numerous medical, school, and therapy appointments led many parents to the point of exhaustion. Parents reported using up sick leave and annual leave when they decided to leave work to meet those demands that led to additional stress.

Despite the challenges experienced with ASD therapies, some parents were relieved at the results. Many saw improvements in children’s behaviors, speech, and social skills yet others thought their child had not improved as much as they would have liked and would have liked to see an individualized approach. Parents who had children in school were faced with additional challenges such as teachers demonstrating limited knowledge about ASD, a lack of student assistants, as well as inconsistencies that was viewed as detrimental for children with ASD. Some parents would need to relocate to larger centers as a means of accessing ASD services. The impact that an ASD diagnosis was having on their families was apparent that placed greater burdens on families living in rural areas.

Realizing the impact of an ASD diagnosis. Parents were recognizing impacts on marital and family relationships, as well as finances. Parents spoke about how caring for their child with ASD was taking priority over their other children’s needs that left them with feelings of guilt. Relationships with partners had either been strengthened or strained:

We stayed married for financial reasons. So it was either file for bankruptcy or live on the welfare system . . . So he has a room in the house and my son and I have the rest of the house. We share a residence and he sees his son when he wants to. When he doesn’t choose to, well we go on with our day unfortunately. It’s not easy. We’re trying our damnest to make it work . . . the divorce rate is high.

Parents expressed their thoughts about what was yet to come. “Contemplative waiting” describes the next phase wherein parents contemplate and anticipate their future with a child having ASD.

Contemplative waiting

In this final phase of the process, the concept of waiting can be described as, “remaining stationary in readiness or expectation.”³⁴ In this phase, parents waited, planned, contemplated, pondered, and anticipated how their children’s future and theirs

might look. Parents also reflected on what was lacking at the time their child received their diagnosis and what might benefit other parents going through the same experience. This phase includes 2 subphases: pondering the future, and reflecting on the past and making recommendations.

Pondering the future. Parents were starting to question what a future might hold for them and their children affected by ASD:

Is he going to have any friends? Is he going to be able to talk? Am I ever going to have any kind of parent-child communication in the regular sense with this kid? Will he grow up to be somebody who has a job and is able to support himself and have friends and a certain level of happiness . . . a happy, healthy life?

Some decided to focus on the present, apprehensive of what lay ahead. “Part of you doesn’t really want to look for the future.” Parents of children with more severe disability were especially concerned because of the high dependency needs of the child:

He’s an only child and when we’re gone I don’t know who’s going to look after him . . . he may end up in a home or some facility being cared for or having workers full time caring for him . . . He’s extremely low functioning probably going to require lifelong care and there’s nobody else to care for him once I’m dead and gone—when he turns 21 then what would you like me to do with him? I’m trying to start thinking of his future.

Parents were wishing for a “normal” and fulfilling life for their children with an aim to integrate into society, get married, have children, and secure employment. Some had begun saving and planning for their child’s future by contributing to registered disability savings plans. As they pondered the future, they also offered recommendations and suggestions for other families facing similar challenges.

Reflecting on the past, and making recommendations. Parents looked back on the services at the time their child was assessed and diagnosed providing recommendations to make the process better for others:

In the beginning, I would have loved support . . . I just want to be able to phone the Autism Society and say, here’s my problem and have somebody say, okay we know what’s going on . . . a lot of time was spent trying to figure where things were and I just didn’t have the energy for that.

They talked about how crucial it was for children to gain early and timely access to diagnostic and treatment services and learning to navigate the health care system was deemed important right from the beginning:

The earlier the diagnosis the earlier you get started on this. I feel like when any parent gets a diagnosis there should be a list like this is what you do. You go here. These are the steps. It would be nice to give a card to a family that’s going through it to say, you can call here and they will give you support—kind of like a helpline.

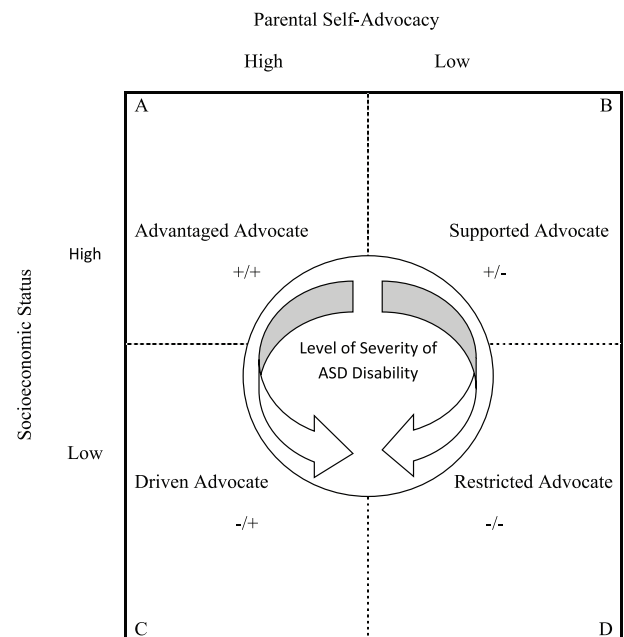


Figure 2. Parental strategies in the process of “Managing the Wait.”

Parents also made suggestions about what they thought the government should provide such as investing in the employment training and support services for adolescents and young adults. They wanted their child to find suitable employment that would enable them to participate in their own futures rather than relying on government subsidies and the welfare system. “He’s going to have barriers to employment. If it’s not addressed, then he’s going to end up being dependent on government subsidies.”

Strategies in “Managing the Wait”

We conceptualize that the core concept governing parents’ experiences of accessing services for their children with ASD is managing the waiting. We developed a 2×2 typology to describe how SES, parental self-advocacy, and severity of ASD symptoms impacted the overall process of managing the wait, with families having different capacities for managing or shortening the wait depending on these factors. Self-advocacy in health care has been described as “standing up for oneself”³⁵ and “a process of internalizing skills and resources to act in a way that supports [clients’] specific needs and goals.”³⁶ In this instance, we describe parental self-advocacy as being assertive, internalizing knowledge, skills, and resources as a means of making decisions on behalf of a child or adolescent diagnosed with ASD with the aim of accessing services.

In Figure 2, we show how high or low SES in combination with high or low parental self-advocacy provides different strategies parents used in “Managing the Wait.” We used dotted lines in our typology to illustrate the dynamic aspect. Strategies vary over time as SES or parental self-advocacy change. If parents move to a higher level of SES or gain experience and knowledge around engaging with the health care system, that

would correspond in a change of strategy. Severity of ASD disability was found to be a critical factor for all families trying to access services.

Parents having *high* self-advocacy skills in a *high* SES status can be described as “advantaged advocates.” These parents are able to move forward and advance in acquiring services for their children because they have both the financial means and high self-advocacy skills:

There was more flexibility . . . you feel more as a consumer of a service when it's [the service is] private . . . a lot of families obviously don't have that advantage, that personal social network that's connected indirectly with autism professionals, got his diagnosis faster . . . we would have been another year for sure getting a diagnosis had we not known people . . . [He] is lucky he's got parents that we're on this.

In contrast, parents who are “restricted advocates” are both financially limited in their ability to pay out-of-pocket expenses and have low self-advocacy skills that lessen their ability to act on behalf of their children. “I don't know what the hell I'm doing half the time with autism . . . I'm scared half of the time . . . I'm a single parent . . . mental exhaustion, financial stress.”

Parents who are “supported advocates” may have the financial means to gain timely access to needed services, yet lack self-advocacy skills:

I'm employed . . . we have insurance . . . basically her [child's] needs are taken care of . . . if we knew more, we probably would have done more . . . it's like we opened the door to this new world of autism and we didn't have a clue.

Parents who are “driven advocates” are strong advocates for their children yet financially disadvantaged. These parents find themselves remortgaging their houses, using credit cards, thus incurring substantial amounts of debt attempting to pay out-of-pocket expenses so their child can have access to services:

You got a wait list and a child that has needs and at least you got a credit card that can fund it or that line of credit . . . we're \$32,000 [in debt] still digging out . . . you do what you have to do . . . Pushing that little bit started at least to get me on to a waiting list for services . . . I had to push. I'm still pushing.

We found that level of severity of ASD disability was a central factor that impacted the process of “managing the wait.” Parents of children with increased disability anticipated they would require additional services throughout the life course of their condition. In contrast, parents of children with less disability thought their children might have less need for services during the life course of their condition. The process of managing time was found to be a dynamic process. Therefore, as parents' SES and/or self-advocacy skills changed, so would their strategy.

Discussion

Findings from this study provide insight into how parents access diagnostic and treatment services for children diagnosed

with ASD. “Managing the wait” was found to be the main concern for parents, which started from the time when they first began recognizing concerning behaviors and continued throughout the life course of their condition.

Parents were often the first to recognize and identify behavioral concerns. Ozonoff et al.³⁷ have also shown that parents often detect ASD concerns earlier than professionals. Parents who express early concerns about their child's nonverbal communication or unusual gestures can receive an earlier diagnosis and timelier access to services.³⁸ We found, however, that extensive delays in accessing diagnosis and supportive services for children with ASD were a more significant issue for families.^{6,15,39,40} We also found that health care providers who either dismiss parents' concerns or reassure them that their child will “outgrow” concerning behaviors contribute to unnecessary delays.⁴¹

Many of the parents in our study expressed an overall dissatisfaction with both the health care and education systems. As a result, they become advocates for their children as well as all families affected by ASD. This has been reported by other researchers who describe how parents of children with disabilities move from being an “advocate” for their own child to becoming an “activist” for all children.⁴²

Parents reacted to an ASD diagnosis for their children with shock, confusion, anger, sadness, and worry. A recent metasynthesis showed parents have mostly negative emotional responses on receiving an ASD diagnosis for their children that included reactions of shock, despair, devastation, resentment, and anger.¹⁸ Research has shown that when parents finally receive an ASD diagnosis, it provides a sense of relief. It legitimizes their concerns, providing evidence to obtain treatment and services for their children.⁴³ Parents in our study expressed a sense of relief about the ASD diagnosis because they finally had a label for what was going on with their child's development. They viewed this label as a means to obtain interventions and supports for their children in an attempt to reduce problematic behaviors related to ASD and increase communication skills. However, despite receiving a diagnosis, we found that parents still were required to “manage the wait” because they continued to face delays in acquiring ASD-related services for their children. Those types of delays have also been widely reported.^{8,10,11,16}

In our study, parents were dissatisfied with the information provided to them at the time of the diagnosis. They believed they had not received enough information about support services, and talked about how certain professionals were not knowledgeable about how they could acquire support. Previous research findings suggest that the number of difference sources of information families receive at the time of ASD diagnosis significantly predict the informal and formal social supports parents receive, and families of low-income report significantly less support.⁴⁴

Parents of children with ASD have additional expenses and added burdens to employment that can turn a middle-income family into a low-income family in a short period of time.

Indeed, many families of children with ASD earn 28% less than other families who do not have a child with ASD.⁴⁵ Health insurance plans do not often cover behavioral-related therapies and consider them educational rather than medical. As a result, parents can be left to pay these costs themselves.⁴⁵ Social and recreational activities specifically designed to benefit children affected by ASD can be expensive. Parents often spend hundreds or thousands of dollars a year sending their children to organized activities such as camps, and social and recreational activities to assist in their child's social and physical development.⁴⁵ In this study, parents described how they struggled to meet these types of financial challenges often paying out-of-pocket for these types of activities considered a benefit for their child.

The findings from this study demonstrate how parents' financial situations changed following their child's ASD diagnosis. Parents described financial hardship, increased levels of stress, hopelessness, and despair as they attempted to meet the financial challenges of parenting a child with ASD. In attempts to maintain full-time employment, parents struggled to balance the many scheduled appointments. This has also been previously reported that parents of children with ASD spend a significant amount of time finding, assessing, and retaining services, coordinating services, advocating for their children, and taking children to appointments.⁴⁶ In this study, we found parents quit full-time work or reduced their working hours to stay at home to care for their child affected by ASD often leaving one parent shouldering the financial burden for the family. That was also evident in other study findings.⁴⁶ Our study findings illustrate how parents end up spiraling into debt in attempts to pay for services and therapies for their children. Parents reported taking out multiple loans or would remortgage their homes in attempts to pay for out-of-pocket expenses deemed necessary in caring for a child with ASD. Similar financial concerns have been raised in other studies^{17,18,27,47}

Health disparities include biological, behavioral, sociocultural, and environmental factors that can influence health-related outcomes.⁴⁸ SES, environment, and geography have reportedly led to disadvantages for parents of children with ASD.⁴⁹ In our study, families living in rural communities and single parent families faced geographical challenges needing to travel long distances to access ASD services only available in urban centers. Other researchers have reported similar findings.^{50,51} Living in a rural area as well as low financial status is associated with receiving a later ASD diagnosis for children.^{52,53}

Our study does have some limitations. We acknowledge that parents' report of their children's diagnostic and cognitive status may be a limitation of this study. Findings from this study may be not generalizable to the general population because of the nature of qualitative research design; however, similar study findings strengthen the likely validity of our results for other populations. The model of findings resulting

from this study and the typology of strategies used by parents impacted by SES, parental self-advocacy, and level of disability is unique that adds to the current knowledge and that can be considered a strength of this study. We focused on the experience of parents accessing services for their children and adolescents. Challenges for families and individuals impacted by ASD continue beyond adolescence into adulthood. As a result, we need further research to explore the processes by which children with ASD transition into adolescence and adulthood to understand the impact on families throughout the entire life course of this condition.

Implications for Practice

It is evident from our study findings that parents are noticing early signs and symptoms of ASD in their children and identifying subtle clues such as limited eye contact, sleep problems, unusual diet, delayed speech, and other related symptoms. Health professionals need to recognize parents' expertise in identifying early signs and involve them in the diagnostic process as early as possible.

Receiving the news that a child has ASD can have a profound effect on the family. Health professionals need to provide an adequate amount of time to deliver the diagnosis and provide support for parents at the time of diagnosis and afterward. Parents may be so overwhelmed at the time of diagnosis that they stop listening and miss important information that the health professional is communicating. The professional needs to present the information clearly in lay language so parents can better understand. Health professionals should schedule a follow-up meeting or phone call after the initial time of diagnosis to provide an opportunity for parents to ask questions, talk about any concerns, and, or ask for resources and supports. Health professionals must also consider parents' financial resources when providing information about treatment and intervention services. They should provide information to parents about any financial resources that may be available for those who need them.

Diagnosis should not be a means to an end but part of an ongoing life-stage process. Professionals must impart a sense of optimism to families about their child's future. Health professionals should recognize children with ASD and their families require lifelong provision, management, and service coordination.

Conclusions

With increasing ASD prevalence rates, not only in Canada but also around the world, it is important for parents to obtain timely access to diagnostic and treatment services for affected children. The health care system needs sufficient resources to be able to provide timely access to diagnostic and intervention services that can benefit individuals with ASD over the life course of their condition. It is also important to address the social justice issues faced by these families. In a country where publicly funded health care is readily available, children and youth with

neurodevelopment and mental health conditions deserve to be cared for at the time they need it so they can reach their full potential and become contributing members of society. Our results offer a unique perspective on families grappling with ASD as illustrated in the dynamic interplay of SES, parents' ability to advocate for a child with ASD, and level of severity of ASD symptoms. Our findings illustrate that strategies used by parents to "manage the wait" to access services for children and adolescence with ASD during the life course of their condition are not static, but ever changing and dynamic.


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Author Contributions

All authors designed the study. RA coordinated data collection. All authors were involved in data analysis, writing, and reviewing the final manuscript.

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