

# “It’s not a user-friendly system”: Mothers’ realities of raising children with Autism Spectrum Disorders

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## Abstract

**Background:** Mothers of autistic children experience the stressors of parenting, as well as the effects of caregiving for disabled individuals. One in 66 children is diagnosed with ASD in Canada, but there is no known cause of the disorder. While research has explored the many effects of ASD and potential therapies and treatments, less is known about the lived experiences of the primary caregivers who support autistic children. This study sought to explore the experiences of mothers raising their biological children diagnosed with ASD in southwestern Ontario.

**Methods:** Eleven mothers participated in one-on-one semi-structured interviews to discuss their children, their children’s needs, and the effects of caregiving for families.

**Results:** Four themes emerged through thematic analysis: *Figuring it out*, *Do your own research*, *We fall in a gap*, and *What about the family?* The themes each have three subthemes further describing the mothers’ experiences. Overall, many concerns existed for mothers raising autistic children that change over time (e.g., noticing the first symptoms, getting a diagnosis, searching for resources, and long-term coping).

**Conclusions:** Mothers who raise autistic children are in dire need of support as they care for their growing children and maintain their own wellbeing. Suggestions have been provided as to how this support may be most effectively provided to families.

## Introduction

Caregivers are an integral component to the Canadian healthcare system, providing hours of unpaid informal support to persons with disabilities and additional needs. Included in this demographic are parents of children diagnosed with Autism Spectrum Disorders (ASD), a neurodevelopmental disorder affecting one in 66 children in Canada [1]. Mothers of autistic children typically function as primary caregivers in families and report feelings of stress that negatively affect quality of life [2]. Specifically, a variety of domains were listed as relevant to quality of life, including parental factors (e.g., gender), disability related factors (e.g., ASD severity), and contextual factors (e.g., household income) [2]. While both parents experienced distress related to raising their autistic children, research has shown mothers have been affected more severely [3]. Further, as compared to mothers raising typically-developing children, mothers of autistic children reported increased stress, fatigue, time caring for children, and work intrusions, along with reduced leisure time and decreased positive affect [4]. Further, O’Brien [5] emphasized the direct and indirect effects of parenting autistic children, such as feelings of ambiguous loss after the diagnosis, which correlated to stress and depressive symptoms. Ho, Fergus, and Perry [6] found similar findings in their qualitative study examining nine families raising autistic adolescents in Toronto. In general, Canadian families raising disabled children faced many obstacles, including education, income, support, and child care [7]. Interestingly, health professionals were among the notable stressors:

“46.7% had doctors or health professionals who took a “wait and see” approach with the child’s disability; 39.3% experienced long waiting periods to get the diagnosis; 29.5% had difficulty getting referrals or appointments; 25.7% could not obtain the diagnosis locally.” (p. 9)

Unfortunately, mothers have been vulnerable to aforementioned stressors, and a myriad of others, when raising their autistic children [8]. This paper sought to understand the experiences of mothers’ raising their autistic children in Southwestern Ontario, specifically over the course of their children’s diagnosis and current access to resources.

## Methods

### Theoretical orientation

To understand the families lived experiences, the theoretical orientation of interpretive phenomenology [9], guided this research. To gain information about said experiences, information rich cases were integral to the research, as well as rigorous methods to ensure credibility. Recruitment and data collection procedures were approved by the university Research and Ethics Board before beginning the study.

### Participants

The authors sought assistance from a local family resource centre which e-mailed a recruitment letter to clients who utilized ASD resources in the past. Eleven mothers agreed to participate, which was sufficient for saturation based on previous literature [10] as well as recurring patterns found throughout analysis.

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**Data collection-**

In order to provide context for the interview a priori, participants completed a short demographic questionnaire about themselves and their autistic children. Each mother participated in a one-on-one semi-structured interview at a time and location of her choice. The interviews were audio-recorded and transcribed verbatim. Each transcript was e-mailed to the participant, where she could add, change, or remove any information [11] she felt necessary. Additionally, in order to identify and bracket their personal experiences, the authors kept journals throughout data collection and analysis, including ideas about which questions should be asked based on previous knowledge, thoughts about the research, and expectations about the findings.

**Credibility**

Triangulation, the process of comparing several points of reference to ensure that a representative outcome is reached, is a key component in establishing credibility in qualitative research. Three forms of triangulation were utilized in this research: data, methods, and researcher [11,12]. Further, the interviewers established rapport with the mothers when scheduling interview times, discussions before and after interviews, and conducting member checks via e-mail.

**Analysis**

The data analysis followed the steps outlined by Braun and Clarke [13], through a phenomenological lens. Analysis of the data revealed recurring themes indicating saturation had been reached; therefore, no more participants were recruited.

**Results**

Eleven mothers of children who had been clinically diagnosed with ASD volunteered to participate in this study. The average ages of the mothers and children were 42.6 years and 11.6 years, respectively. Nine of the eleven mothers had more than one child and all mothers resided in Southwestern Ontario, Canada (Tables 1 and 2). Interviews were conducted at participant homes or workplaces, local coffee shops, an office at the university, or on the phone. On average, the interviews were 67 minutes in length, ranging from 36 to 111 minutes of recorded time. Four themes emerged upon analysis of the transcripts (Table 3), as well as how many mothers directly addressed each subtheme. Key quotes from each subtheme have been listed in Table 4.

**Figuring it out**

All mothers commented on the challenges of raising children who demonstrated atypical developmental milestones or ASD-like behaviours, not only in determining their needs (Something's Up), but

**Table 1:** Demographic information of mothers.

Pseudonym	Age	Level of Education	Marital status	Employed
Carolyn	51	'Some university'	Married	No
Deb	49	High school	Married	Yes: Full time
Justine	40	College	Married	Yes: Full time
Natasha	40	College	Married	No
Vicky	41	High school	Common law	Yes: Full time
Bailey	29	College	Separated	Yes: Part time
Cara	45	College	Single	Yes: Full time
Wendy	45	University	Married	Yes: Full time
Hannah	44	College	Married	Yes: Full time
Brenda	45	University	Married	Yes: Full time
Susanne	41	Master's Degree	Married	Yes: Part time

**Table 2:** Demographic information on children.

Parent Pseudonym and (Child Pseudonym)	Sex of child	Age of child at time of study (years)	Diagnoses (mm/yyyy)
Carolyn (Lisa)	Female	18	12/2014
Justine (Nathan)	Male	10	03/2015
Deb (Dane)	Male	9	10/2012
Natasha (Emily)	Female	6	11/2014
Vicky (Andrew)	Male	14	NA/2008
Bailey (Tyson)	Male	6	01/2016
Cara (Zoe)	Female	16	05/2008
Wendy (Jack)	Male	10	12/2012
Hannah (Timmy)	Male	16	04/2006
Brenda (Steve)	Male	17	11/2002
Susanne (Michael)	Male	6	07/2013

**Table 3:** Themes and subthemes from one-on-one semi-structured interviews with 11 mothers of children with Autism Spectrum Disorder and the number of mothers who directly discussed the subtheme in their interview.

Theme	Subthemes	N (out of 11)
Figuring it Out	Something's Up	11
	Jumping Through Hoops	11
	Hurry up and Wait	7
Do Your Own Research	Uncovering Your Child's Needs	9
	"Roadmap of Resources"	11
	Therapies and Alternatives	8
We Fall in a Gap	Funding: Too Little Too Late	11
	Programming	9
	Mental Health	7
What About the Family	Mother's Resources	11
	Respite isn't an Option	7
	"The Whole Family Needs Help"	10

also in attaining a diagnosis (Jumping through Hoops) and navigating the healthcare system (Hurry up and Wait).

**Something's up**

Eleven mothers described the years and months leading up to their children's ASD diagnosis. Some mothers felt a "gut instinct" or mother's intuition. Mothers highlighted the difficulty to diagnose "high-functioning" ASD in a young child during a 15-minute doctor's appointment, and one advised mothers to write down instances where something seemed "off" with the child to provide examples to a physician during routine check-ups.

One mother found it difficult to maintain composure when the physician was adamant her child did not have ASD. While some mothers had gut instincts, others did not notice any symptoms. Some mothers were unaware or in denial of any out of the ordinary behaviour, such as Cara who said "... autism was the Rain Man, that wasn't my daughter." Many believed their children were experiencing typical childhood development or that it was just a boy thing, or perhaps he/she was just shy.

The early years appeared to be a balancing act between searching for an explanation and allowing the children to grow and develop at their own pace. One mother felt the sooner she attained a diagnosis, the sooner her child could receive help, reducing the gap between him and his peers. On the other hand, another mother said she was hesitant to seek a diagnosis because she did not want to compare her child's development to other children. This seemed especially challenging for first time mothers to discern, because they did not have another child to compare.

**Table 4:** Key quotes from each of the sub-themes.

Subthemes	Key Quote
Something's Up	"One way is trust your gut. Definitely, if you feel there's something different, if you are in the park and you notice, why is my kid doing that? If you're asking yourself questions um that aren't the typical, oh how do I relieve teething? Or is this gas or is this not gas? Like if you're asking why is my kid not doing this? ... like trust that, you know. Don't mind exploring that with your partner or with friends or with the doctor. And don't always take the first answer, you're ok to get second answers." – Bailey
Jumping Through Hoops	"... So it took a good year to get diagnosed, it wasn't something that was sudden... Again what happens is that you are referred to a place and what happens is that they spend a specific amount of time with you and then eventually say sorry we can't help you and then they put you to the next person and then that person puts you to the next person. Like I said it's a vicious circle that literally goes nowhere... I mean other thing like I said one diagnosis is for a lot of these organizations too. You need to provide them with assessments with data. A lot people, if I wasn't able to get my psych assessment paper myself, I would've never been able to obtain any of the resources because they require specific information to get the resources and every place is different. So what one person can take as a psych. ed., they might want the data the next place." – Justine
Hurry up and Wait	"... we're starting private OT therapy. They have it at the school but we're on our waiting list and we haven't received it as of yet, we have been on the waiting list since um, over a year now I think." – Natasha
Uncovering Your Child's Needs	"I do a lot of looking online. And just reading different blogs and different articles and seeing all the different stuff about different families with their kids that are on the spectrum. And I guess it's kind of comforting knowing that you're not the only one, which I know. And then there's so many stories that I'm like, 'I can relate to that, I can relate to that, I can relate to that.'" – Vickie
"Roadmap of Resources"	"... I find the system here very disjointed. It is hard to find information. And to know everything that is available out there, like you would have to be on half a dozen mailing lists to know everything that is going on. And a lot of it is overwhelming." - Brenda
Therapies and Alternatives	"... you're an expert of your child, but you're certainly not an expert of the system, right. So I think you end up going down some dead ends quite often. Um unless you know somebody or you can call somebody." – Wendy
Funding: Too Little Too Late	"... so that's the problem, Dr. Scmitt, we were seeing her up until, just the beginning of October, it was continuous every 2 weeks going to see. Which was okay because we can do that but it comes to a point, like some people don't have benefits and its 185 dollars an hour and its 50, 50 minutes appointment. So we were fortunate that we can, can do it um we used up all of our benefits, the consultation, like the psychological assessment was over 3 thousand dollars just to get her assessed." – Carolyn
Programming	"I contacted, I don't remember who they were, but they said, 'there really is no resources for him at this point because he is 16. But when he turns 18 you could retry and see if there is anything to help with his independent living.' Which he wouldn't need because he is high functioning. That is what they said. They said 'if he did mainstream school. And he is high functioning there is no services here for you.'" – Hannah
Mental Health	"... depression was big especially when he hit puberty. Another thing people don't realize, he was on Adderall before puberty. He was stabilized on it for so many years because he started on it when he was little. And we just originally started it to slow him down, to teach him coping skills and then take him off. But you forget and you get complacent... But it was the mix of the artificial and the natural chemicals that all of the negative side effects of that medication came up, to the point of suicidal ideations, suicidal attempts... It took an emerge. visit and an emerge. doctor – not an autism specialist, not a psychologist, not a social worker – but just a straight out emerge. visit saying 'you know that some of the side effects are this this and this'. And you forget because it was years ago that you read about them. So we stopped [the medication] immediately and it all subsided. All of the [suicidal] behaviours stopped." – Brenda
Mother's Resources	"I think it's good to have support groups. Um I haven't really joined any. I haven't really done that. Um, not something I wouldn't entertain, but where do you get the time for it? Right? It's good to have support groups but then you're taking time away time from other things that could be helping him. Because a support group isn't helping Jonathon, you know what I mean?... the flip side of it is [pause] you lose grasp with the rest of the world, like not every child is like this, you have to deal with reality, right?" – Deb
Respite isn't an Option	"... you're running on high speed non-stop. There's no break. There's no one that comes in and says "ok, I'm going to take over, you go and lay down" or "you go and do this." Like wherever I went, my children were with me. Didn't matter where I went. There was no mom time. Mom time was driving from my house to work. That was my time and that was it." - Cara
"The Whole Family Needs Help"	"Yes. I think every family, because that is another thing that is important. With ASD it is the whole family that needs help. Not just the kid. And I think it would be really helpful if every family went through some sort of workshop or therapy or whatever you want to call it. An introduction to this world. And it can't be everything in one shot because it is too much. Like at least the parents, they need time with everything." - Susanne

Unfortunately, some mothers wished they were more persistent with physicians or acted on their intuitions sooner. Years later, it became clear for many that something was happening in those early years of life. Mothers wished physicians would have probed more into the social milestones of development (e.g., communication, eye contact, etc.) rather than solely motor and feeding. That said, mothers hoped early childhood educators could identify concerns that may have been missed, meaning symptoms may be detected within the first years of daycare or preschool.

**Jumping through hoops**

Another challenge faced early in development was the amount of time and resources required of the mothers. The diagnostic process had taken months to years for many of these families. Many mothers felt it was difficult but necessary to rule out other potential diagnoses, such as hearing issues, Attention-Deficit/Hyperactivity Disorder (ADHD), sensory processing, receptive language disorder, Obsessive-Compulsive Disorder (OCD), etc. It was not uncommon for mothers to be referred back and forth between different healthcare professionals during this time and they were expected to coordinate between many doctors and specialists. Some opted to pay for private specialists who could offer a shorter wait time if they could afford the additional expenses.

Others had to leave town to reach specialists, like Brenda, who drove for months to doctor appointments three hours away in order to avoid the waiting list.

In addition to challenges with healthcare specialists, some mothers experienced challenges with medicating their children. It was recommended for both Bailey and Cara to address their children's symptoms through medication, but this was a stressful decision for both. "You never want to medicate a six-year old", said Bailey. Cara explained her daughter had to try more than one medication in order to find the best fit for her symptoms and side effects. There were also reports of long-term consequences from ASD-related medications. Brenda felt her son's suicide attempt was related to his medication use during childhood. Healthcare professionals mentioned mental health issues were a common side effect of his medication, but no one tracked these issues over time. Further, mothers sought additional "psych assessments" later in life, such as after their children entered the school system or moved into a different age group.

**Hurry up and wait**

Not only did mothers wait for specialists, seven also reported waiting on services. At the time, many felt attaining the diagnosis was the hurdle, only to find out they would have to wait for therapies and

services. It was a stressful time for many mothers, as they worried about their children waiting for services and missing important developmental milestones. They understood that the "high-priority" cases of ASD were first in line for these services (e.g., those who were lowest functioning), but that also meant the higher-functioning children waited months to years for important services. These wait times put them at risk for falling even further behind their peers. Even more frustrating, just as children outgrow clothing, they also outgrew the specialists or service age group. For instance, if a child was on the waitlist at age four and then attended school, he was removed from that waitlist and moved to the school wait list. Some mothers made choices between services because of the wait time, such as forgoing intensive behavioural intervention (IBI) because the applied behaviour analysis (ABA) wait list was shorter. Navigating the health care system was an uphill battle causing frustration for all the mothers.

### Do your own research

All mothers explained they were responsible for uncovering and seeking out resources for their children. Particularly, mothers spent a great deal of time reading about ASD and researching therapies that would best support their children's unique needs. Mothers also highlighted their need for help to find services and supports available for their families. The most significant support mothers felt would help in raising their children was a "one-stop-shop" for ASD information and resources.

### Uncovering your child's needs

A challenge described by nine mothers was determining the needs of their children. Several mothers had little to no understanding of ASD in general, such as how it is diagnosed, the levels of severity, or effective treatments. Some found reading about ASD in books and online was helpful, while others did not. Mothers reported it was difficult to identify their children's concerns due to the spectrum nature of ASD and the vagueness of published materials. For instance, reading was challenging for some mothers because what they found was not reflective of their children. As a result, mothers discovered various parenting techniques by "trial and error" until something seemed to resonate with their children. Lack of verbal skills made it particularly difficult when deciding if therapies and/or medications were necessary. Mothers had to judge their children's behaviours, facial expressions, and mood to determine if they were suffering. In this way, mothers became experts at reading their children's body language to try to understand their needs. When mothers discovered which routines worked, they tried to maintain a schedule as long as it seemed to be effective.

Once mothers began to understand these needs, they had to "pick [their] battles" based on the behaviours of their autistic children as compared to their own energy levels. For example, it required patience to coach a child to dress himself, but he was capable if given enough time. Unfortunately, mothers did not always have the time to allow their children to practice these skills. Some mothers (e.g., Wendy) allowed their children to act differently each day based on how they were feeling, because that is the nature of raising children. Other mothers (e.g., Hannah) were more regimented.

As mothers learned more about their children, they felt it was their responsibility to educate others. Not only did they have to describe their children to each ASD specialist during the diagnosis and treatment process, they also had to educate family members and school teachers. Mothers recalled it was difficult for some people to "stomach" the diagnosis, such as their husbands or parents. Some

grandparents believed the children's behaviours were simply the result of "bad parenting". Mothers described the necessity in helping others to understand how their children were different from other autistic children, let alone typically developing children.

### "Roadmap of resources"

When discussing the mothers' needs for raising their autistic children, it was common to hear about the confusing and impractical nature of ASD resources, including parent groups, social supports, system navigation, camps, activities, extra-curriculars, and playgrounds. All mothers spent a great deal of time researching what was available because there was no "one-stop-shop" that covered the variety of resources they were seeking. Not only did the time-consuming nature of research cause mothers stress, they also worried about missing something or making mistakes that could be detrimental to their children's development. While many recognized it was difficult for physicians to suggest a course of action due to the variability of ASD (e.g., as compared to diabetes), mothers felt they had to become the expert of what resources were available. Mothers dedicated time and energy into researching, much of which led to dead ends (see *we fall in a Gap*).

One mother said the system was disjointed, in that some organizations tried to keep clients to maintain or secure financial support, even if there were better options elsewhere. Some specific issues that arose during these discussions was the need for physical resources such as weighted vests and timers, which were primarily available online, and therefore inaccessible. Finding summer camps was also a challenge, because many had limited spaces available and registration was often months in advance. Not only did parents have to secure a place for their children at camp, but some also had to secure a one-on-one support person for their children, which posed further challenges.

A mother's support group was discussed as helpful, if it focused on parenting techniques rather than "complaining" about the challenges of parenting autistic children. Mothers could suggest resources for other mothers and mentor families with a new ASD diagnosis about how to navigate the system, such as when camp registration happened and which resource centres were most helpful. Some mothers had personal or work connections that aided in their search for research, while others went to a service centre that highlighted local resources and/or were given a binder of options. That said, mothers who had these supports still struggled to find resources at times. Cara raised her child in a rural town and experienced amplified accessibility concerns as compared to families living within the city: "I feel like I'm an island. I'm on my own and have been. And don't even know how to even access the help or even ask for it." Mothers were empathetic to parents raising autistic children who spoke English as a second language or who recently moved to a new city. Doing this research was time consuming for mothers, as lamented by Carolyn: "... is this going to be my life?".

### Therapies and alternatives

Eight mothers felt it was their responsibility to be versed in the treatment options for ASD and to discern which were appropriate for their children. For instance, mothers had to explicitly request a particular therapy (e.g., occupational therapy) from their physician or felt they were educating their physician on therapeutic options a result of their own research (e.g., Susanne). It was difficult for mothers to discern how much to "push" physicians for alternatives such as homeopathy and nutritionists. Some mothers (e.g., Debra) felt supported when the

pediatrician provided suggestions as to which therapies to pursue over time, but this experience was less common. Alternatively, others were given a list of therapeutic options, but did not understand their purpose or know when they were needed (e.g., IBI vs. ABA).

Mothers felt certain therapies and alternatives were not intuitive, and they would not have known to research them in the first place. Cara learned about therapies and alternatives that would have benefited her daughter, had she found them earlier in her daughter's life. Wendy felt her experience with ASD therapies went more smoothly than others because of her background in the field of mental health. Some mothers were optimistic their needs would be met over time (e.g., Bailey, 6-year-old son), while others were not because their needs had not been met thus far (e.g., Brenda, 17-year-old son). Further, children may have benefited from a therapy at the time, but then regressed after the session was completed, and therefore the therapy research and application process began again.

In addition to therapies, mothers sought other forms of support. Susanne wanted regular care for her child, but not simply a babysitter who would watch her son, but someone with experience who could stimulate him and help him progress. A common stressor associated with researching therapies was the extensive paperwork required to apply for the service. Altogether, mothers expressed difficulties researching and attaining therapies and alternative treatments for their autistic children.

### We fall in a gap

Many challenges associated with raising autistic children are rooted in the spectrum nature of the disorder. These differences created issues for *Funding*, *Programming*, and *Mental Health* resources because any inclusion criteria will exclude part of the population from accessing said resource. Mothers felt there were few resources for autistic people in the Region of Waterloo, and that they were excluded from many of these programs for a variety of reasons.

### Funding: Too little too late

All mothers felt their autistic children did not receive the financial support necessary to cover costs of therapies, programming, respite, and any other resource necessary for their development. For example, one mother said the government funds developmental disorders such as Cerebral Palsy because there are known medical expenses (e.g., physical therapy). However, this was not the case for autistic children, where many children with high functioning ASD are a lower funding priority. This was particularly difficult to swallow for mothers of high functioning children, who often fall behind their peers and experience social consequences.

Mothers reported applying for government support was tedious. Further, funding opportunities required parents to pay for the service first (e.g., pay for camp), and then apply for money afterwards. This process left families in financially unstable situations until the money was provided, and at times, deterred mothers from utilizing services altogether. Cara reflected on her financial situation, saying "...Like food or assessment? I'd love the assessment, but I can't." She had to choose between feeding her family or helping the development of one child over the other. Similarly, Bailey explained medication costs caused financial strain, while Vickie said "... they're out of my reach" when discussing summer camps.

Financial support varied amongst mothers in this study based on their income, ASD severity, and the funding representative with whom

they worked. For instance, some mothers had a financial representative who helped find and secure funding for their children's expenses. On the other hand, some mothers did not have any representative, or they had a representative who was not well versed in the opportunities available. Mothers reported a variety of federal, provincial, and private funding opportunities for their autistic children and some services billed directly to these funds, which was most convenient for mothers.

Some mothers could afford out-of-pocket expenses to reduce service wait time. In other words, families who were wealthier could pay to receive support more quickly. Alternatively, many were unable to afford private services because the costs were astronomical (e.g., \$150 CAD/hour according to one mother). One mother said she could advocate for lower costs of these services, but by the time any changes were made, her child would no longer benefit. In this way, mothers had to "*pick [their] battles*", and sometimes it was easier to pay for additional supports.

A myriad of factors could affect funding provided to each family, including benefits packages from a parent's work. Some families had more coverage, but not all plans covered necessary services, such as Occupational Therapy. Further, some mothers were frustrated they did not qualify for funding based on their total family income, as they still felt they did not have the finances to support all the needs of their autistic children. Overall, funding caused a divide between families; those who could afford services and those who could not. Mothers felt this gap had far reaching effects for their children's development and wellbeing.

### Programming

Within the theme of *We fall in a Gap*, nine mothers discussed their experiences with programming for their autistic children. It was challenging to find programming that offered the right level of support for their children. For example, some children required minimal additional support within a "*regular*" program rather than the extensive support in some "*special needs*" programming. In addition to finding programs with the right amount of support, finding programs coinciding with the children's interests or maturity levels was also challenging. For instance, some programs were "*too kiddie*" for teens or were just for boys.

Many programs were inappropriate for autistic children due to their unique sensory needs. For instance, basketball in a gymnasium required participants to deal with excessive noise, which was challenging for many autistic children. Similarly, Bailey said there were few playgrounds that offered positive sensory experiences. Mothers expressed a need for individual activities that provided gainful experiences in a low-stress environment. Wendy reported her son enjoyed physical activities (e.g., biking) rather than group activities (e.g., soccer). Hannah described her son's difficulty with swimming due to the pressure of skilled performance to pass. Hannah experienced a gap in programming, because although there were several swimming programs, none suited her needs. Programs that emphasized enjoyment rather than skill (e.g., horseback riding) would be better suited for autistic children.

Mothers made suggestions to improve program accessibility and appropriateness for autistic children. First and foremost, programs were too expensive. Mothers understood many programs were more costly (e.g., need for specialized equipment), but they did not feel that should be their own expense. Additionally, mothers wanted "*gainful experiences*" for their children, such as employment, volunteer, or life-skill opportunities. Mothers felt their children needed experiences to

develop self-worth and independence, such as learning how to handle money and cook for themselves. These experiences would help autistic children to thrive as independently as possible while growing into young adults. Similarly, there should be support in universities and colleges for students with ASD to navigate new schedules and environments.

### Mental health

In addition to the subthemes discussed above, seven mothers mentioned *Mental Health* as an area where supports were lacking. Mothers understood the negative aspects of the ASD diagnosis on the mental health of their children; specifically, they worried their children would limit themselves because of their diagnosis. For example, mothers were concerned their children would use ASD as a "crutch" during difficult situations, rather than overcoming challenges. While many mothers did not want to label their autistic children, it was certainly required for securing supports (e.g., funding, individualized education plan). Mothers felt that it was their responsibility to preserve their children's self-esteem due to any negative experiences arising in schools or the community.

Moreover, mothers were concerned about bullying because their children were often treated differently or segregated from typically-developing children. Mothers felt bullying affected the mental health of autistic children, especially if others made their children feel different, unintelligent, or disliked. Many sought programming and resources that allowed their children to be accepted as they were, rather than constantly trying to fit in. Further, mothers thought bullying led to social withdrawal, as social engagement often highlighted their differences from other children. In this way, the "invisible" aspect of ASD affected social engagement. Unfortunately, these concerns sometimes occupied the views of other family members, whereby mothers had to defend the needs of their children to their parents.

Depression and anxiety were two mental health concerns highlighted. While not all mothers discussed these issues, it was a significant talking point for those who experienced it and therefore it was deemed a necessary subtheme. Depression was experienced by some autistic children and negatively influenced their feelings of self-worth. Further, prolonged medication use was attributed to depressive symptoms in some children, which mothers associated with two attempted suicides (Brenda; Vickie) among the 11 children.

Unfortunately for Vickie, her son's depression was not only related to medication, but his experiences with bullying. Similarly, Wendy commented on her son's anxiety as it pertained to his ASD, saying he worried excessively. Not only did the children experience mental health issues, but also the parents. Mothers commented they often felt alone (e.g., "I'm an island" – Cara), overwhelmed, and in need of emotional support. Many focused on the needs of their children in the interviews, but it was clear mothers struggled as well.

### What about the family

While most of the interviews were spent discussing the children (e.g., the three themes previously discussed), mothers also talked about their own needs, as well as the needs of other family members. It was evident ASD did not only affect the children, but also their families.

### Mother's resources

All mothers discussed resources they personally needed to raise their autistic children. When asked what she needed in order to raise her son with ASD, Bailey simply stated "help". She then went on to say

her income was not enough to support two children, especially when one required therapies and medications. Among the other resources listed were parent support groups where mothers could discuss their experiences raising autistic children, but that were divided based on their children's ASD severity (e.g., a high functioning group and a low functioning group). For instance, Wendy discussed her discomfort in attending a mother's support group because her son's needs were minor as compared to other group members. She felt uncomfortable talking about her challenges (e.g., how to help her son in a regular classroom) with other mothers because their experiences were so much more severe (e.g., child was not allowed to attend school due to aggressive behaviours).

Similarly, some mothers showed no interest in support groups because they did not find them useful. Instead, these mothers felt that psychologists or counsellors specifically trained in ASD would be the most helpful resource. In this way, mothers could discuss their challenges and stressors, but they could also receive advice about how to raise their children. Some mothers gained advice from the mother's support groups, but this was less common. In support groups, mothers reported others "complained" about their issues, making it an undesirable environment.

In addition to formal resources (e.g., funding, support groups, psychologists, counsellors), mothers were also in need of informal support from friends and family. Many found it isolating raising autistic children because their social networks could not identify with their experiences. Often mothers lost friendships because their time was consumed raising their autistic children. Further, some friends did not understand ASD and felt their children were unsafe together. One mother talked about the fact that her autistic child did not play with others on the playground, which further isolated the families from each other. In this way, mothers became more distant from friends and experienced difficulty creating new relationships.

Mothers' parents (e.g., children's grandparents) were both described as supportive and unsupportive in the interviews. Some mothers relied heavily on grandparents as additional supports for raising their children, while others could not rely on them at all. One issue emerged from grandparents' lack of understanding about ASD. Mothers felt grandparents were judging their parenting abilities, specifically, that their children could act more "normal" if they had more discipline and routine. Not all grandparents viewed ASD in this way, but for those who did, mothers felt it was due to generational differences of thinking.

The third area of support listed was from employers, particularly regarding job flexibility. Missing work or going in late often occurred due to their children's needs on a particular day. Gaining employer understanding of their unique parenting situations, was helpful for mothers on days that were more difficult than others. Employer understanding decreased stress associated with parenting and perhaps, if more employers were understanding of ASD, more mothers would choose to work full time.

### Respite isn't an option

Seven mothers expressed a deep need for respite care in a variety of different forms. Their lives were consumed by raising their autistic children and respite was considered necessary for their personal well-being. Unfortunately, the respite options available often fell short of their needs. Seven mothers discussed specifically their challenges in finding and financing respite care. Some mothers felt the government support for respite was sufficient for their needs, while others did not. Cara for

example, did not have respite care, could not rely on her mother, and had limited resources for her family.

Not only would respite affect the mother, but also other people in her life, such as her spouse and children. For instance, having respite care would allow both parents to leave the home and be together. Respite would also allow autistic children to attend camp or participate in school trips, two circumstances where typical adult support would not be sufficient for autistic children. In these cases, respite supports would allow autistic children to gain similar experiences as their peers.

On a day to day basis, mothers wanted to find babysitters with specific skills and traits, such as those with previous ASD experience or who could be patient with their children. In this way, not only would the child be cared for, but he or she could also be challenged to grow and learn rather than simply being supervised. Vickie described difficulty finding a babysitter who could handle taking care of her son when he was younger. Clearly, mothers needed more supports to take time for themselves and allow their children to be more independent.

### **"The whole family needs help"**

Ten mothers discussed the influence of ASD on family members, including siblings and spouses. Eight mothers had two or more children, and seven discussed how ASD affected the relationships between typically developing siblings and their siblings with ASD. Bailey described the relationships between her son with ASD and his younger brother, saying *"the only friend that he ever talks about really having is his brother."* Similarly, Cara discussed the way in which her stepchildren supported and cared for her autistic child, saying *"they're very close knit"*.

Other mothers, however, noticed strained relationships between their children, to the point that the siblings would benefit from their own supports and resources. Vickie said her children interacted as any other teenage siblings but wondered whether a family support group would be beneficial. The dissimilarities among sibling relationships was influenced by differences in age and functionality, and age at the time of this research. Hannah said her other children were *"not really affected"* by her son with ASD, but her husband had difficulty accepting the diagnosis. Five mothers discussed their husbands when considering their family's experiences with ASD, including Carolyn, whose husband disliked Nelly's ASD diagnosis. Vickie described her husband spending time outside in the evenings opposed to inside with the family, saying *"I think it's just to escape. He likes to hide outside a lot."*

Due to the difficulty for family members to accept the diagnoses, three mothers highlighted the importance of couples or family therapy to gain acceptance and cope together. Wendy said her husband sought counselling after the diagnosis, which was beneficial for their relationship. Undeniably ASD permeated the lives of all family members, (or ASD affected the family systemically), not just mothers, as denoted by Susanne *"...with ASD it is the whole family that needs help. Not just the kid."* Counselling and support groups were suggested as helpful resources, especially if family members were having a particularly difficult time accepting the diagnosis.

### **Discussion**

Mothers faced many challenges when raising their autistic children, from attaining an ASD diagnosis to determining whether their children had mental health concerns. Specifically, mothers felt they had to learn about their children's needs, the most effective therapies, and available resources on their own.

The political climate for mothers raising autistic children in Ontario has not been supportive of autistic children's needs, with the burden primarily falling on mothers. Dudley and Emery [14] argued *"Relying on family to shoulder the lifelong burden of care in the face of inadequate service and supports is not a sustainable model of care."* (p. 25). Yet, this is how mothers have experienced raising their autistic children. In Ontario, funding for families raising autistic children has seen extreme structural changes [16]. These changes have affected accessible funding amounts for families raising autistic children in attempts to shorten the waiting time for resources. For most families, this means their access to funds has been reduced, so they cannot afford paying for the services, therefore, reducing waitlists.

Mothers in this study discussed similar experiences to those in other Canadian cities [6,15] and in other countries [8]. However, governments that have systems in place to meet the needs of disabled children early in life could reduce their healthcare costs in the long run. One mother contended:

*"If they don't help with these children when there 9, there is going to be a huge cost when they are 20 and they cannot succeed... They will cost the government a substantial amount of money, if they don't give money to help them succeed as a child; it's just the way it is."* – Debra

Stapleton and colleagues [17] conducted a cost-benefit analysis on Individualized Education Plans for disabled children and found a return of \$0.47 for every dollar spent during schooling years. In this way, arguments about funding cuts due to unaffordability lose traction because governments could see a return on investment by supporting childhood development. While it is important not to reduce families raising autistic children to dollars and cents, cost-benefit analyses have been necessary for regulatory decisions within the Government of Canada [18].

It is imperative to address the needs of other family members such as mothers, spouses, and siblings, with respect to respite care, overall family functioning and family counselling. Although much research on therapeutic and medical interventions for autistic children exists, there has been less emphasis on interventions for the family effects of ASD. Vasilopoulou and Nisbet [2] reviewed 12 qualitative articles assessing quality of life for mothers and fathers and described a need for interventions to increase quality of life, specifically physical health. Similarly, Lock, Hendricks, Bradley, and Layton [19] discussed supports like "family fun days" and support groups, although mothers in this study felt support groups did not address their overall needs. In the present study, mothers said support groups relieved feelings of isolation, but they would not necessarily help to solve other needs, such as waitlists, funding, and respite care.

Giarelli, Souders, Pinto-Martin, Bloch, and Levy [20] conducted an intervention for parents of autistic children, offering three additional hours of personalized nursing time in addition to the typical one-hour consultation and treatment plan information sheet. There were no differences in perceived stress or personal impact of diagnosis between the intervention and control groups [20], suggesting a long-term approach may be more effective than acute interventions. The mothers in this study said they saw physicians for short periods of time and/or there was too much information to sort through after diagnosis. What mothers wanted was ongoing support to assist them in finding and securing resources at different stages of their children's lives.

Social media could be one form of ongoing support to connect healthcare providers with families. In Saudi Arabia, Hemdi and Daley [21] utilized an instant messaging app to educate and support mothers

raising autistic children, which significantly reduced stress and clinically reduced depression over time. While this form of intervention could reach more families (e.g., rural and remote), the authors suggested it be augmented with other services such as respite [21]. Mothers in the present study and in past research have expressed great need for respite services when raising autistic children [4].

Respite time was shown to have a direct link to the marital quality in 101 mother-father dyads raising autistic children, both indirectly (e.g., reducing stress, increasing daily uplifts) and directly [22]. Respite care in the form of day programs has been shown to improve mental and physical health and reduce caregiver burden in those caring for frail elderly people [23]. The review by Whitmore [24] found that respite was associated with higher stress in some circumstances, such as parents in need of formal care due to burnout from caring for their autistic children. Whitmore [24] called for additional respite research, creativity in practical application (e.g., unique solution for each unique family), and support from policy makers for parents, support professionals, and researchers.

The findings from this research point to the importance of a "family ASD representative" who could help parents find the resources, therapies, and funding best suited for their autistic children. This representative could find supports for both autistic children, such as camp funding, as well as their caregivers, such as respite, in addition to helping families complete funding paperwork. Gray [3] found that use of support services decreased as autistic children aged into teenagers and young adults, not because the need for supports declined, but because of the limited resources available for adults with ASD. Further, Hare, et al. [25] reported parents of adults with ASD experienced distress and unmet needs. An ASD representative would be most helpful in connecting families with resources already in existence, but could also determine which resources are missing and advocate to local and provincial organizations for more support.

Whitmore [24] contended mothers raising autistic children experienced "chronic stress comparable to combat soldiers" (p. 630). There are still many gaps in resources for families raising autistic children, including funding, programming, and mental health. It is also imperative to address other family members such as mothers, spouses, and siblings in respite care and family counselling. The political climate has not been supportive of mothers raising autistic children. As such immediate aid in the form of finances, counselling, and resource management is warranted, potentially in the form of a family ASD consultant.

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