# Understanding the Role of Formal and Informal Support Resources for Parents of Children with Autism Spectrum Disorder

Kaitlyn Avery, Tricia van Rhijn and Kimberly Maich

## *Abstract*

This research examines the extent to which parents of children with autism spectrum disorder (ASD) perceive support resources to be available, accessible, and/or effective in supporting their needs. A focus on the impact of the COVID-19 pandemic in the availability and effectiveness of service delivery is included. A total of 35 parents in Ontario, Canada with a child aged 6–17 with ASD completed an online survey responding to questions about involvement in ASD services, use of formal and informal supports, important support needs, which needs were being met, and perceptions of unmet needs, all which were thematically analysed. The analysis demonstrates that parents experience multiple barriers in accessing supports, particularly from formal sources. Further, the barriers were heightened during the pandemic particularly in relation to the multiple role responsibilities that parents had to take on due to a discontinuity of support provision. Most of these parents put their own support needs aside to focus on their child, with the support their child receives directly relating to the ability to attend to their own needs. Parents identified challenges related to uncertain funding, limits of a one-size-fits-all model of support, and lengthy waitlists. Recommendations for family-centred care and the need for service coordinators to work with families to assist in navigating the complex support system are provided.

Keywords: Autism Spectrum Disorder; parenting; formal support; informal support

**Kaitlyn Avery** is a recent graduate of the Family Relations and Human Development program (MSc) at the University of Guelph and holds a Bachelor of Arts in Social Psychology from McMaster University. Her research interests include families of children with disabilities, particularly autism spectrum disorders, as well as policy development and program design in support of a family-centred service system.

**Tricia van Rhijn** is a Registered Early Childhood Educator and an Associate Professor in the Department of Family Relations and Applied Nutrition at the University of Guelph. Her research interests include early childhood education and care, family relations, work–life integration, and the experiences of non-traditional students in formal postsecondary education, in particular mature students and student parents. Recent publications include: Squires, K., van Rhijn, T., Harwood, D., & Coghill, M. (2021). Outdoor learning as a way forward during the COVID-19 pandemic and beyond. *eceLINK Peer Reviewed Collection, 5*(2), 21-33. https://hdl.handle.net/10214/26529; van Rhijn, T., Underwood, K., Frankel, E., Lero, D. S., Spalding, K., Janus, M., Friendly, M., & Haché, A. (2021). Role of child care in creating inclusive communities and access for all. *Canadian Public Policy 47*(3), 399-409. https://doi.org/10.3138/cpp.2021-010; and Balter, A., van Rhijn, T., Gores, D., Davies, A. W. J., & Akers, T. (2021, advanced access). Supporting the development of sexuality in early childhood: The rationales and barriers to sexuality education in early learning settings. The Canadian Journal of Human Sexuality. https://doi.org/10.3138/cjhs.2021-0034.

**Kimberly Maich** is a Registered Psychologist, Board-Certified Behaviour Analyst (Doctoral), Ontario Certified Teacher, and a Professor in the Faculty of Education at Memorial University. Her research interests focus on autism spectrum disorders. Recent publications include: Maich, K., Penney, S., Alves, K., & Hall, C. (2020). Autism spectrum disorders in the Canadian context: An introduction. Canadian Scholars.

## *Introduction*

It is clear that families of children with autism spectrum disorder (ASD)[1] would benefit from increased social support, improved access to specialized services, and a foundational family focus on service delivery (Ekas et al., 2010; Luther et al., 2005); yet parents continue to experience limited accessibility and availability of resources or supports. Social support encompasses both formal and informal resources that provide instrumental, informational, and practical support (Cobb, 1976). Yet, parent perceptions of support resources as inaccessible are largely attributed to services that do not consider diverse family structures and experiences or the way that families are embedded within multiple social systems. Parents of children with ASD often name fewer people who support them as compared to parents of neurotypical children, with their partners and immediate family being the most common means of such support (Boyd, 2002). Unsurprisingly, ASD-related research tends to focus heavily on the challenges and difficulties faced by parents, whereby stress is a direct result of raising a child with ASD. Because of this narrow perspective, research must explore support resources beyond the immediate family to include informal social networks and formal resources while considering the perceived adequacy of support. Therefore, the current study was undertaken to understand the meaning of support resources for parents in acknowledgement of the bidirectional and reciprocal parent-child relationship. This paper explores the self-reported needs of parents of children with ASD to understand how they perceive the role and availability of support, and subsequently understand their need for these resources in their daily lives.

To explore the support needs of parents, it is important to understand the context of this project as there is variation across Canadian provinces and territories related to ASD funding and service delivery. In Ontario, for example, the Ontario Autism Program (OAP) funds services for children and youth under the age of 18 through age- and income-based funding criteria (Government of Ontario, 2019). Service delivery in Canada, and particularly Ontario, has been described as overburdened (Brown et al., 2012). The unmet support needs of parents continue to be attributed to and a direct reflection of a system that has difficulty "keeping pace with the demands placed upon it" (Brown et al., 2012, p. 506). The primary challenge for Ontario's ASD-related service delivery system is ensuring that families receive interventions and formal support based on their unique needs. In this paper, we discuss the current literature that exists around the role of social support for parents, including issues with continuity and access to coordinated care and systemic barriers to service access that contribute to disparities in accessible and equitable services. This research examines the extent to which parents perceive support resources to be available, accessible, and/or effective in supporting their needs. A focus on the role of the Coronavirus pandemic (COVID-19) in the availability and effectiveness of service delivery and how COVID-19 has impacted parental abilities to carry out multiple roles within and outside of the home is included.

---

[1] This paper uses person-first language (i.e., "children with ASD"). In doing so, we acknowledge the complexities behind ASD and recognize the importance of identity-first language for the Autistic community.

*Literature Review*

Both the number of supports received and the quality of those supports shape perceptions and experiences for parents of children with ASD. The benefits of social support stem primarily from perceived support, which indicates the extent to which parents regard themselves as being cared for and supported (Benson & Karlof, 2009). The perceived availability and accessibility of support appears to be more important than the actual receipt of support, suggesting that parents benefit from the belief that resources are available. Additionally, parents will first rely on their spouse or partner as a form of social support (Boyd, 2002; Ekas et al., 2010). Spousal support can be a protective factor in mediating the impact of adverse events and increasing the quality of support provided within the family (Aydogan & Kizildag, 2017). It is likely that parents are comfortable relying on each other, rather than discussing private family matters with unfamiliar networks. Placing more emphasis on spousal support can result in parents who are equally distressed, unable to effectively support one another, and experience high levels of unmet needs (Hartley & Schultz, 2015).

In general, informal support is more effective for parents and can play a powerful role in reducing negative experiences through advice, assistance, encouragement, and understanding (Hartley & Schultz, 2015). Alternatively, formal support has less significance for parents, but can help meet the needs of parents when used alongside informal support. Formal support, such as government funded programs and professional-based organizations provide parents with information, training, and education that is needed to navigate the service system. Parents of children with disabilities use support services to the same extent as other families but to a lesser degree that is not consistent with their needs (Kazak & Wilcox, 1984). Further, families with children with ASD extend considerable effort to locate and access needed specialized support and, accordingly, experience more difficulty than families with non-disabled children in obtaining support (Rivard et al., 2015). Existing support services—particularly formal services—are not aligned with individual family needs and often result in parents who must repeatedly battle for information and push for accessible resources (Galpin et al., 2018). Current services may not utilize a family-centred approach, which can result in parents who feel isolated, unheard, unsupported, and have difficulty maintaining resilience when presented with challenges. These feelings can also be attributed to external sources, such as society's lack of understanding about ASD, stigmatization from social networks, and an unsupportive service system. The difficulties faced when obtaining services or gaining accessible and appropriate information is one of the most significant challenges for parents of children with ASD.

Due to services that do not adopt family-centred approaches or consider how family life has been altered to accommodate their child's needs, parents can struggle to balance their multiple role responsibilities. Continuity of support and access to coordinated care are major issues for parents who place their necessities aside to ensure their child's needs are met (Hoogsteen & Woodgate, 2013). Parents often cite themselves as the main case manager for their child and are responsible for navigating the educational, social service, and health care systems for their children (Desmarais et al., 2018). The development of overlapping roles is the result of parents who attain multiple roles within and outside of the home, including advocating, organizing, tutoring, educating, and caregiving to support their child to cope, adapt, and learn needed skills to support

their demanding roles. Participating in multiple roles takes a considerable amount of time and energy from parents that ultimately leaves little time for themselves. The time spent between multiple roles highlights the resources and support needed for parents to maintain care for themselves and their family. Parents of children with ASD engage in complex and intense arrangements that are required to successfully balance home, work, and community responsibilities (Freedman et al., 1995). They spend more time developing an intense knowledge base of ASD and coordinating appropriate services for their child—role responsibilities that require immense support for parents who leave their own needs behind.

For parents and families to be adequately supported, numerous non-family members need to become involved and familiar with the family's needs and regular routine. Although several potential sources of support exist, the need for relational and emotional support as well as resources for information, guidance and materials are identified by parents as being needed (Derguy et al., 2015). This extensive list of support needs underscores the need for support from professionals, as having the knowledge and skills related to ASD does not appear to be enough for parents to feel sufficiently supported (Derguy et al., 2015). Systemic characteristics that promote or obstruct service use—affordability, availability, and accessibility—are important when determining parents' perceptions of social support. Parents who already feel unsupported also feel they do not have the same resources to engage with different types of support. While the Ontario Autism Program (OAP) is purportedly based on the principles of coordination and continuity of services, family-centred care, and evidence-based development (Government of Ontario, 2019), parents still identify that resources are inadequate to address their support needs (Galpin et al., 2018). Ensuring that support services are centralized and coordinated is an important path to reducing the discontinuity that many families still experience (Brown et al., 2012).

The impact of an inadequate service system continues to weigh on families, with the stress of service acquisition and barriers to service access culminating in multiple unmet support needs. Perceived unmet needs refer to parental judgement of the discrepancy between their actual access and what is normative or desired (Brown et al., 2012). Structural factors within the service system contribute to disparities in accessible and equitable services that perpetuate unmet needs for parents. Barriers to service access include a lack of family-centred, culturally aware services, insufficient information about services and funding, financial costs, and the complexity of the service system itself (Brown et al., 2012; Derguy et al., 2015; Mackintosh et al., 2005; Stahmer et al., 2019; Woodgate et al., 2008). Parents may experience significant difficulties navigating the system and, even when support is available, such supports can be perceived as difficult or impossible to access (Galpin et al., 2018). These structural factors may eventually culminate in parental dissatisfaction, distress, and an overall sense of mistrust in the system. It is for this reason that parents name fewer people who support them and rely heavily on personal relationships. Parents consistently endorse needs related to professional agencies and partners working with their families as being unmet but emphasize the importance of these services in mediating burdens such as out-of-pocket expenses (Siklos & Kerns, 2006). These inconsistencies are a key barrier within the service system preventing families from accessing the services they need. While Canada has seen a growing awareness of services and improvement in access to such services due to successful parental advocacy (Volden et al., 2015), it is important that supports are modified to fit the needs of families through parent-professional partnership.

Given the importance of social support, especially during times of increased strain and reduced access to services, this study investigated parental perceptions of the availability, accessibility, and effectiveness of support services to meet the needs of their child with ASD and family and the impact of the COVID-19 pandemic on parental abilities to carry out multiple role responsibilities within and outside of the home.

## *Methodology*

Following institutional ethics review, parents in Ontario, Canada who had a child aged 6–17 with ASD who lived with them 50% or more of the time were recruited from social media, ASD advocacy groups, and organizations providing ASD services (e.g., Autism Ontario, Kerry's Place, Thames Valley Children's Centre). This study focused on parents with children aged 6–17 because the Ontario Autism Program focuses its funding on children younger than 6 acknowledging that children in the older age bracket would have decreased funding and limited treatment options that could lead to unmet support needs for parents. Data collection occurred via Qualtrics (www.qualtrics.com), an online survey platform.

## *Participants*

A total of 35 parents who met the inclusion criteria and completed at least 90% of the survey questions were included in this current analysis. Parents were primarily female (32 females and 3 males) and averaged 40.1 years of age (range: 31–50). Detailed parent characteristics are included in Table 1.

**Table 1**

**Parental Demographics**

| Variable | | Other | *n* | Mean/% | SD |
|---|---|---|---|---|---|
| Gender | Male | | 3 | 8.57% | |
| | Female | | 32 | 91.43% | |
| Age | | | 31 | 40.10 | 5.84 |
| Ethnicity | White | | 24 | 68.6% | |
| | Black | | 3 | 8.6% | |
| | South Asian (e.g., East Indian, Pakistani, Sri Lankan, etc.) | | 2 | 5.7% | |
| | Chinese | | 1 | 2.9% | |
| | Latin American | | 1 | 2.9% | |
| | Aboriginal Peoples of North America (North American Indian, Métis, Inuit) | | 1 | 2.9% | |
| | Other, please specify | Jewish, Samoan, Pacific Islander | 2 | 5.7% | |
| | Prefer not to answer | | 1 | 2.9% | |
| Relationship Status | Single, never married | | 3 | 8.6% | |
| | Common-law | | 5 | 14.3% | |
| | Married | | 25 | 71.4% | |

| Variable | | Other | *n* | Mean/% | SD |
|---|---|---|---|---|---|
| | Separated | | 2 | 5.7% | |
| Education | No schooling completed | | 1 | 2.9% | |
| | Some high school, no diploma | | 2 | 5.7% | |
| | High school graduate or equivalent | | 1 | 2.9% | |
| | Some college credit, no diploma | | 4 | 11.4% | |
| | Graduated from college | | 9 | 25.7% | |
| | Bachelor's degree | | 7 | 20.0% | |
| | Master's degree | | 10 | 28.6% | |
| | Other, please specify | Doctorate | 1 | 2.9% | |
| Employment Status | Employed | | 20 | 57.1% | |
| | Self-employed | | 1 | 2.9% | |
| | Out of working and looking for work | | 2 | 5.7% | |
| | Out of work and not currently looking for work | | 4 | 11.4% | |
| | Unable to work | | 6 | 17.1% | |
| | Other, please specify | Laid off, Stay at home mom | 2 | 5.7% | |
| Yearly household income | Less than $20,000 | | 4 | 11.4% | |
| | $20,000 to $34,999 | | 3 | 8.6% | |
| | $35,000 to $49,999 | | 2 | 5.7% | |
| | $50,000 to $74,999 | | 9 | 25.7% | |
| | $75,000 to $99,999 | | 7 | 20.0% | |
| | Over $100,000 | | 8 | 22.9% | |
| | Prefer not to answer | | 2 | 5.7% | |
| Location | Urban (city, suburbs) | | 27 | 77.1% | |
| | Rural (countryside, towns, outside commuting zone of larger urban centres) | | 8 | 22.9% | |
| Number of Children | 1 | | 10 | 28.6% | |
| | 2 | | 17 | 48.6% | |
| | 3 | | 5 | 14.3% | |
| | 4 | | 2 | 5.7% | |
| | More than 4, please enter number | 5 | 1 | 2.9% | |

### *Characteristics of the Children*

Participants also provided demographic information for their child with ASD (Table 2). The average age of the participants' child was 9.17 (range: 3–17) with a majority identified as male. All the children were diagnosed with ASD with an average age of diagnosis of 5.32 years (range: 2–13). Participants shared the functional independence of their child via three options: requiring support, requiring substantial support, and requiring very substantial support. There were 15 participants who said their child required support, six who said their child required substantial support, and three who said their child required very substantial support. Ten participants did not select a concrete category, but provided narrative clarification via an "Other, please specify" option. Most participants discussed the variation in their child's support requirements, thus choosing not to label functionality. Participants noted that support depended on age, activity,

environment, or circumstances. Finally, participants identified any comorbid conditions that occur alongside their child's ASD. Of the 45.7% ($n=16$) of participants who responded yes, various comorbid conditions were identified, with the most common conditions being an anxiety disorder (e.g., generalized anxiety disorder, separation anxiety), Attention-deficit/hyperactivity disorder (ADHD), and various learning disorders.

**Table 2**

**Child Demographics[1]**

| Variable | | $n$ | Mean/% | SD |
|---|---|---|---|---|
| Gender | Male | 26 | | |
| | Female | 8 | | |
| | Non-binary | 1 | | |
| Age | | 35 | 9.17 | 3.68 |
| Diagnosis | Autism Spectrum Disorder (ASD) | 35 | | |
| | Autistic disorder | 0 | | |
| | Asperger's disorder | 0 | | |
| | Pervasive developmental disorder—not otherwise specified | 0 | | |
| Age at Diagnosis | | 31 | 5.32 | 3.53 |

[1]Participants who had more than one child with an ASD diagnosis were asked to think about only one of their children between 6 and 17 years old for the duration of the study.

*Materials*

This study adopted a qualitative approach including a researcher-created questionnaire. Participants were asked about their involvement in ASD services, their use of formal and informal supports, their important support needs, which needs were being met, and their perception of unmet needs. These questions helped to gauge parental knowledge of and perceived need for support resources in Ontario. Examples of questions include: demographics (e.g., "What is your current employment status?" "What has your child been diagnosed with?"), parental involvement in and perception of the Ontario Autism Program, parental lives during COVID-19 (e.g., "What changes occurred to your support services due to COVID—loss or cancellation of services, change to remote delivery?)," and parental perceptions of receiving and accessing support (e.g., "Do you find it easy to seek out support or ask for help?"). In addition, the Family Support Scale (FSS; Dunst et al., 1984) was included to determine the sources of support that parents utilized. The FSS measures support from family, friends, social groups, and professional agencies, and service providers, whereby higher scores equate to greater amounts of support (Dunst et al., 1984). Participants rated the level of perceived helpfulness on a 5-point Likert scale ranging from "not at all helpful" to "extremely helpful." The 19-item FSS organizes forms of support into three subscales: kinship support (5 items; e.g., immediate family, spouse), informal support (9 items; e.g., friends, coworkers, other parents), and formal support (5 items; e.g., professional helpers and agencies).

*Data Analysis*

The survey data were thematically analyzed (Braun & Clark, 2006) using NVivo (Version 12) to identify the dominant themes provided by the participants in response to questions about service use, the OAP, and COVID-19. Braun and Clarke's (2006) six steps were followed to analyse these data: data familiarization, generating initial codes, searching for themes, reviewing themes, defining, and naming themes, and producing a final report. This type of analysis was useful for the current study as it allowed the participants' experiences to be analyzed while considering a family systems perspective. Additionally, thematic analysis was not only useful for describing parents' experiences with support resources, but to further explore how parents view the role of social support to influence their family lives.

*Results*

When asked about service use characteristics and their experiences with support resources, if they receive needed supports, most parents commented that they did not receive needed supports or explained where supports were lacking, outlining accessibility barriers, financial constraints, limited community-based supports, and programs that are not centred around their child's individualized needs. Four themes were found in the participants' identification of supports they rely on: kinship, formal, informal, and support from self or partner. Kinship support included the participants' parents and immediate family (e.g., grandparents, stepparents). Formal support included professional helpers and services such as counsellors, therapy teams, psychotherapists, and educational assistants (EA). Parents discussed previously being involved with behaviour therapists and ASD support workers, as well. Parents who cited informal support included the Autistic community, other parents of children with ASD, and local support groups. Participant #35 said that "other parents/support group who are going through the same thing… [have] been my biggest help."

Most parents negatively viewed the process of seeking out support, attributing this to both internal and external factors. Some parents struggled because of their stubbornness, not wanting to overburden others, or not knowing where to look. Other parents found it difficult due to COVID-19 restrictions, waitlists, financial constraints, and a service system that offers restrictive support. Parents who responded positively explained that they frequently advocate for themselves or their children and know the language required to ask for help. Participant #63 said that "it is easy because I am his voice and his advocate and it's my responsibility to persist no matter what." Another parent said that they know it is not a weakness to ask for help and that their child needs a community of people to help their family.

When parents were asked if anything was preventing them from accessing support, 85.7% responded with yes or explained what has prevented them. Parents cited multiple reasons, such as financial and location constraints, little support from the government (e.g., long waitlists to programs, limited funding), and a lack of accessible services. Additionally, there were multiple resources that parents required but could not access for themselves and their children. These supports included EA or school-based supports, social groups for children, specialized therapies

(e.g., speech-language or occupational), applied behaviour analysis (ABA), and support groups for parents.

To measure perceptions of available supports, parents indicated the perceived helpfulness of kinship support, informal support, and formal support. Using the 19-item Family Support Scale (FSS), participants were asked to rate the level of perceived helpfulness of each source listed, including family members, friends, community members, and professional agencies. The variables within the FSS will be reported on as categorical and descriptive statistics will be provided due to missing data and multiple questions where the source of support was rated as not applicable. The sources rated as not applicable include church members/ministers, co-workers, and early childhood intervention programs. Almost all the participants (82.9%) rated church members or ministers as not applicable and 51.4% of participants rated both co-workers and early childhood intervention programs as not applicable. Furthermore, 34.3% of participants rated both their children and neighbours as not applicable and the remaining participants rated these two sources as largely unhelpful. In comparison, the sources of support that were rated as most helpful and had limited missing data were: the participants' spouse or partner, professional helpers, their parents, school, or childcare centres, and the family's or child's physician. The descriptive statistics for the FSS can be found in Table 3.

**Table 3**

**Descriptive statistics for the Family Support Scale (FSS)**

| Variable | $n$ | Mean | SD | Helpfulness Rating [a] |
|---|---|---|---|---|
| Spouse or partner | 33 | 3.79 | 1.27 | 57.58% |
| Professional helpers (social workers, therapists, teachers, etc.) | 25 | 3.06 | 1.16 | 37.14% |
| My own child(ren) | 23 | 2.61 | 1.37 | 34.78% |
| School/childcare centre | 32 | 2.78 | 1.36 | 31.25% |
| My parents | 30 | 2.83 | 1.39 | 30.0% |
| Early childhood intervention program | 17 | 2.71 | 1.69 | 29.41% |
| Co-workers | 17 | 2.41 | 1.42 | 23.5% |
| My spouse or partner's parents | 25 | 1.88 | 1.27 | 16.0% |
| My friends | 33 | 2.36 | 1.14 | 15.15% |
| My family or child's physician | 35 | 2.54 | 1.17 | 14.28% |
| Professional agencies (public health, social services, mental health) | 31 | 2.10 | 1.08 | 12.9% |
| Other parents | 22 | 2.14 | 1.08 | 9.09% |
| Social groups/clubs | 26 | 2.27 | .96 | 7.69% |
| Parent groups | 27 | 2.19 | .74 | 7.41% |
| My relatives/kin | 30 | 2.00 | 1.05 | 6.67% |
| Neighbors | 23 | 1.65 | .98 | 4.34% |
| My spouse or partner's relatives/kin | 27 | 1.48 | .80 | 3.7% |
| My spouse or partner's friends | 28 | 1.57 | .92 | 3.57% |
| Church members/minister | 6 | 1.67 | .82 | 0% |

[a] The percentage of participants who rated the source of support as "very helpful" or "extremely helpful" based on how many answered each question.

Parents who currently receive services for their children discussed the changes to service delivery during COVID-19, which included the switch to remote or virtual delivery. The changes to service delivery resulted in families not being able to access the services their children needed and, at times, a complete cancellation of social programs and activities. Parents discussed limited opportunities for service access through remote delivery and little support for their families and are not suitable for their child's ASD. As participant #45 wrote:

> [Services have] stopped. [There was] no contact or support from our ABA team… we moved to remote sessions for 15 minutes per day, which takes an hour to set up for. It was stressful and disorienting.

The stress of engaging in virtual appointments was reiterated by other parents whose children are receiving limited time with their regular professional service providers. Even with restricted service options, many children were not interested in participating, were unable to focus during video calls, and had a hard time adapting to the loss of face-to-face therapy.

There were a small number of parents who reported that remote delivery resulted in less stress and greater consistency for their children. Virtual learning had eliminated stress that can be prompted by overwhelming educational environments and has allowed children to participate in virtual programming that they otherwise would not have access to (due to location and time constraints).

Alongside adjusting to virtual service delivery, families were learning to mediate the impact of losing structure and a regular, daily routine. With school closures and restrictions on social gatherings, the activities and programs that kept families engaged with others had diminished. Participant #67 said, "the loss of school structure and normal routine, followed by the inability to do any of the normal activities my son likes [is hard]." Parents discussed how their children have lost recreational activities, social skills classes, and activities that assist with sensory needs. Parents were worried about seeing a regression in their child's social and developmental progress, as social activities were cancelled for the foreseeable future. For example, parents indicated that without a schedule that includes routine programming, their child became overwhelmed and intolerant of transitions. Many parents said that it is hard for their child to connect with people wearing masks, as it prevents them from reading facial expressions. Others were worried that their child's future would be significantly impacted, which caused anxiety and worry. Participant #65 said that "all I think about is what their future is going to be like. It is a very scary situation to think about." Participant #62 shared similar thoughts: "I just worry that my son won't be able to have a future [due to COVID]."

A small number of parents identified that they were less stressed with the adjustments and changes to their normal routine, but most parents were learning to adapt to working from home while caring for their child(ren). Others had been laid off or had quit work permanently to care for their child(ren). Parents struggled with adapting to the changes of supporting their children at home and learning to stimulate them without leaving the house. Some struggled to meet their child's needs due to reduced service access and fewer opportunities for socialization. Parents were overwhelmed from having few breaks in caring for their children and missed the support they

received from external sources before the pandemic. For example, one parent said that they were "struggling with feelings of isolation and difficulties accessing support from friends. I miss the incidental support that conversations with my colleagues at work gave me" (#5). Ultimately, the disruptions to a normal routine and family cohesiveness resulted in parents feeling tired and fatigued. Some parents did not explain their response and simply stated that they were "very tired," or "tired all of the time." Other parents discussed that they were tired due to an irregular sleep schedule, constantly worrying about their child's safety, and trying to do everything for their family—a life that is not sustainable.

Parents offered insight into how they were coping and taking care of their mental health and well-being during the pandemic, identifying counselling, psychotherapy, medication to mediate mental health impacts, and taking time for self-care. As one parent discussed:

> I have engaged in reading for myself and taking more time for myself… Decluttering and organizing can be calming for me. I have also started to partake in certain activities I dropped in the past, such as drawing and doing arts and crafts. I also spend time with my children by teaching them to cook or doing crafts [or] having movie nights (#52).

Some parents engaged in individual activities, such as meditation practices, self-reflection, and walks since restrictions were put in place; others found comfort in regularly talking to friends or seeking support from groups of parents with children on the spectrum. One parent reported directing all of their energy into supporting their child; however, this coping mechanism was described as "very unsustainable" if it were to continue (#63). On a broader level, parents were trying to take everything one day at a time and take breaks when needed. These responses included one parent who established work-life boundaries by "[setting] limits on work to help and not booking meetings over the lunch hour" (#5).

## *Discussion*

The primary purpose of this research is to examine the role of formal and informal support resources in the lives of parents of children with ASD. This study followed a qualitative research design whereby 35 participants completed an anonymous, online survey. The survey included both closed- and open-ended questions, in addition to the Family Support Scale (FSS). The survey assessed participants' involvement in ASD services, their perception of how services and support networks meet their family's needs, and the external factors that influenced these aspects. The following discussion reviews and integrates the findings of this study to address the overall objective of examining parental perceptions of available, accessible, and effective resources. The following section includes strengths, limitations, and recommendations for future research.

To understand the role of support and sources of support (e.g., instrumental, emotional, informational, financial) utilized, parents were asked to identify whom they rely on for support and if they receive the support required to best support their child. Many parents felt as though

they do not receive the necessary support and prioritized the needs of their child over their own. Parents did not specifically comment on whether they feel supported, but instead framed their perceived level of support in terms of how supported their *child* was (e.g., receiving government funding or treatments). Parents commonly framed their support in terms of their child and in consideration of the impacts on the entire family. Understanding how parents talk about and frame sources of support is an important step in understanding the availability and effectiveness of service delivery. Parents who did not identify themselves when discussing support appear to put their support needs aside to focus on the needs of their child. These parents valued early childhood interventions and treatments, suggesting that the level of support a child receives is directly related to parental emotional state and ability to attend to their own needs. These findings imply that the family unit is seen as the most important and reliable system. It is possible that due to the nature and presentation of ASD, parents view the role of support more holistically and family-centred, thus contributing to the limited focus placed on their own needs. However, external systems equally impact support; parents in the current study perceive external sources of support to be largely inaccessible and ineffective in supporting the needs of their child, thus being ineffective in supporting their own needs. Families reported that they do not receive adequate government funding, have limited access to treatments and services, and experience prolonged waitlists. Furthermore, while some parents had not sought out support for themselves, they did not hesitate to put the time and energy into advocating for their child.

Parents identified several sources of support that they found helpful, including professional helpers, extended family, and school and childcare programs; however, the most consistently reported source of support was their spouse or partner. A majority of parents relied on themselves and their partner because they both intimately know what their child needs and understand how their child learns. Parents valued a partner who understands the experiences of parenting and caring for a child with ASD. This finding is similar to the essence of "living in a world of our own"—a theme described by parents in Woodgate et al.'s (2008) study. Parents of children with ASD often name fewer people who support them—their partner and immediate family are the most common (Boyd, 2002; Ekas et al., 2010; Jones & Passey, 2004). The current findings are similar, whereby parents appeared to be increasingly self-reliant due the perception that external sources were generally unhelpful. The pandemic context may also have contributed to this finding with social distancing and stay-at-home orders limiting access to formal services, even those accessed prior to the pandemic, and tangible and incidental supports from extended family and friends.

These participants viewed the service system as inaccessible in many ways related to funding restrictions, confusing and difficult application processes, lengthy waitlists, and agencies that lacked the appropriate resources and knowledge. Despite parents who said they are often tasked with acquiring the knowledge and skills necessary to find services, these resources are not enough for parents to feel sufficiently supported (Derguy et al., 2015). Parents were not satisfied with the current process of finding formal services, such as the OAP. As was found in previous research (e.g., Brown et al., 2012; Derguy et al., 2015; Mackintosh et al., 2005; Stahmer et al., 2019), these barriers are the most frequently reported among parents of children with ASD and contribute to the maintenance of an unsupportive service system. As Luther et al. (2005) and Meadan et al. (2010) found, parents assume a bulk of the responsibility for meeting their child's needs, putting their own needs aside and sacrificing a part of themselves. Parents in the current

study were concerned with how the government had not provided adequate family services, health care access, or included parents in the decision-making process. It is worth noting that Stahmer et al. (2019) found that factors such as race, education, and income often drive service utilization; however, participants in the current study were White, well-educated, and employed. These findings suggest that despite these privileged demographic factors, the service system is still inaccessible to families.

It was important for parents in the current study to interact and build relationships with professionals that would meet the diverse needs of their child and their own parenting. These parents reported feeling that not only was there insufficient attention to early interventions/treatments and involving parents in the process, but also that they focused much of their time and energy on locating resources. Similar to Siklos and Kerns's (2006) study, these unmet needs are representative of the government's role in providing support to families with children with ASD. Despite being in Ontario where formal support provided by the OAP is touted as a fundamental resource that provides funding and access to treatment for families, parents do not perceive professional agencies to be attuned to their needs. This perspective was not unanimous across responses, as several parents valued the support that the OAP has provided to their family and specifically their children. Further, these parents rated the helpfulness of professional agencies in the Family Support Scale (e.g., public health, social services, mental health services) among the lowest-rated sources despite citing positive experiences with professional helpers (e.g., social workers, therapists, teachers). This contrast suggests that while parents struggle with accessing available government services, they view social workers and therapists as integral to supporting their needs.

The current findings support a role theory approach to understanding parents who experienced an increase in role responsibilities. This increase in responsibilities was due to both having a child with ASD and parenting during the pandemic. A persistent problem for parents of children with ASD is allocating time and energy to balance roles within and outside of the home. As previous research findings suggest, parents attain multiple roles within the home (e.g., educator, advocate, caregiver) due to a discontinuity of support from formal services and the time spent between these roles highlights the support needed for parents to navigate their demanding roles (Desmarais et al., 2018). The theme of overlapping roles was found within the current study, whereby parents were working from home, navigating the service system, and adapting to alternate forms of service delivery. What distinguishes parents in this study from previous research are the implications of COVID-19 on increasing the burden placed upon families to maintain a cohesive work-life balance. COVID-19 has disrupted families' regular routines and parents are adapting to working from home while simultaneously helping their children adapt to remote learning. Parents cannot continue to sustain multiple demanding role responsibilities as they are already feeling stressed, overwhelmed, and burnt out. Resilience can be a predicting factor in how well parents adapt, cope, and perceive themselves as efficacious in the parenting role (Bayat, 2007; Whiting et al., 2019). The current study supports that parents were actively adopting healthy coping mechanisms to mediate feelings associated with poor mental health. Parents were spending more time with their family, setting limits and boundaries to achieve work-life balance, seeking out counselling or medication, and learning to take things one day at a time. The current study did not specifically aim to evaluate how resilience impacts parents of children with ASD, but it is an important finding when considering the factors that influence parents' perception of support.

*Recommendations and Implications*

The current research contributes to a growing body of literature that focuses on families with children with ASD and addresses the support needs of parents in Ontario. The findings from this study provide some understanding of the factors influencing parents' perception of support; accordingly, many parents focused on the support provided through the OAP and were uncertain about what the proposed program will provide for their families in the future. The presentation of ASD is heterogenous and child-specific (Anagnostou et al., 2014; Gentles et al., 2019), which is an important facet when considering the future of the OAP. The current program is an income and age-based program, meaning that there are restrictions on how much funding families receive and where they can spend the money. This framework has resulted in a one-size-fits-all model of support that does not work for many families. The OAP should consider the individual needs of children and their families and implement a needs-based program. Social services have historically been a doing rather than a reflective occupation (Birbili & Tzioga, 2014), and the Ontario government needs to reflect on evidence-based research to approach issues with relative effectiveness. Policymakers and researchers who collaborate with parents to improve the centralization and coordination of services help ameliorate the barriers faced by parents. The government's new core services plan was announced as a well-rounded ASD program, yet parents insist that the plan cannot truly be a needs-based program when government continues to place age requirements and limits on how much funding each child receives (D'Mello, 2021). Several parents criticized the government's arbitrary age funding cap that decreases access to intensive therapy and increases out-of-pocket expenses or even a cancellation of therapy for families that cannot afford to fill the gaps in therapy (D'Mello, 2021; MacMillan, 2021). In addition, parents worry that the introduction of annual assessments would mean a return to benchmarks—a system where children "lose funding if they are not meeting expected milestones, or exceed them" (MacMillan, 2021). Parents and ASD advocates continue to express their concern over the new program details and encourage the government to consider the impacts on families.

Parents in the current study were also concerned about the lasting impacts of lengthy waitlists. Some parents are still waiting to receive funding from the OAP while others waited a minimum of three years before receiving funding, causing worry amongst families. As of March 2021, there are currently 46,169 children registered in the OAP and no new child has come off the waitlist since the OAP waitlist was frozen in July of 2018 (Government of Ontario, 2021; Streck, 2021). Parents suggest that waitlists need to be eliminated due to the importance of critical interventions at an early age. In 2018, Autism Ontario conducted a province-wide survey to understand the current needs and experiences of caregivers and autistic adults. Over 70% of caregivers reported long waitlists as the largest barrier to accessing service (Bardikoff et al., 2018); unfortunately, the situation has not changed and parents in the current study continue to cite long waitlists as a major source of stress and barrier to services. The Ontario government's core clinical services plan will only include 600 children invited to participate in the program, leaving thousands of families with unavoidable wait times and uncertainty (Government of Ontario, 2021).

With this in mind, the Ontario government, service providers, and future researchers should work to further enhance parental involvement in the assessment, diagnosis, and treatment process, in addition to the development of a needs-based ASD program. Parents must not be overburdened

with too many supports and services, without first understanding what each family needs. Parents in the current study discussed difficulties navigating the complexity of available formal supports due to a lack of guidance and advice from trusted professionals. It is crucial that ASD supports are provided from a family-centred perspective that is based on the child's needs and offered in a variety of ways (e.g., in-person, self-directed). Additionally, families require a service coordinator or professional who can implement service navigation, whereby parents can understand what services are available to them, assist in case management, and provide direct support. This should be an important step in building trustworthy parent-professional relationships.

### *Limitations and Strengths*

Although the data collected from the participants provided insight into the effectiveness and availability of support resources for parents, there were several limitations in this study. The first limitation was the small sample size. Small sample sizes can be problematic because they are not representative of the entire population, thus attributing greater variability in the data (Gliner et al., 2016). Additionally, the majority of the participants (91.4%) identified as women and only 8.6% identified as men. While this is a common limitation in ASD-related research, whereby it is assumed that mothers are the primary caretakers of children with ASD (Boyd, 2002; Bromley et al., 2004; Siklos & Kerns, 2006), it is important to recognize that fathers have different parenting experiences than mothers and face unique challenges in accessing or seeking support (Hartley & Schultz, 2015). For this reason, future studies should focus on targeted recruitment to reach a larger proportion of fathers and better understand their support needs. Additionally, many of the participants who completed this study were White, well-educated, and employed. This demographic trend poses a limitation, as the results may not be generalizable to all members of the target population. Similar to previous research (see Bromley et al., 2004; Brown et al., 2012; Mandell & Salzer, 2007), the parents who participated in this study experience and exist within a specific set of privileges that include having access to a computer, a stable Internet connection, and being able to commit more time and energy to complete the survey. By emphasizing online recruitment, this research privileged the practices of dominant groups (e.g., White, middle-class) who are more comfortable sharing their experiences and may further marginalize parents who themselves are disabled. Moving forward, it is important to consider how diverse and non-dominant groups (e.g., visible minorities, working-class, Immigrants) can be represented in the research process (Antony-Newman, 2019).

One of the primary strengths of this study is its contribution to an understudied area of research and an under-examined aspect of parents' lives. To date, there are limited studies that address the role of external sources of support for parents of children with ASD (see Derguy et al., 2015; Desmarais et al., 2018; Galpin et al., 2018; Jones & Passey, 2004; Luther et al., 2005; Sivberg, 2002). Previous literature has focused on the impact of having a child with ASD on parents' mental health and has framed the child as a source of stress to the family. Focusing on the external factors that impact family life (e.g., barriers to service access, accessibility of the OAP, availability of support during COVID-19) is important to expand this area of research. Findings from the current study demonstrate how families are embedded within their social environment

and often rely on sources outside of the family for support, making it important to focus on the heterogeneity of families. Further, with previous research suggesting that ASD is a large source of parental stress (Boyd, 2002; Gray & Holden, 1992; Mandell & Salzer, 2007), findings from the current study can be used to provide insight into the bidirectional parent-child relationship and how family functioning changes across time and in response to different life events.

*Conclusion*

The current study provides valuable contributions to an understudied population: parents of children with Autism Spectrum Disorders (ASD) in Ontario. More specifically, this research contributes to an understanding of parental perceptions of social support and the influence of the Ontario service system on the ability to access support. The results suggest that parents experience multiple barriers while trying to access support, particularly from formal sources, which was heightened during the pandemic. This research places a strong emphasis on recognizing the multiple role responsibilities that parents maintain due to a discontinuity of support and the need to provide family-centred care. A main goal of the current study was to understand how parents perceive the role of support for themselves. An overwhelming majority of parents are putting their own support needs aside to focus on their child, with the support their child receives directly relating to the ability to attend to their own needs. While this study has provided a deeper understanding of how parents frame support, further research on a family-centred approach to ASD services is needed to develop an accessible and equitable service system.

Parents play a vital role in accessing services and treatments for their children. The current study plays a role in highlighting the support needs of families across Ontario and reinforces that there are still gaps in relation to addressing these needs. This study illustrated the numerous families that access social support while demonstrating the distinct areas that parents are primarily concerned about, such as lengthy waitlists, age-based limitations on funding, and being solely responsible for navigating a confusing service system. While the current findings focus on the experiences of Ontarian parents, their support needs cannot be addressed without the government's adherence to community engagement and the development of parent-professional relationships. By focusing on an inclusive and family-focused approach to services, the diverse needs of Ontario families can be examined to develop support that is available, accessible, and effective.

## *References*

Aydogan, D., & Kizildag, S. (2017). Examination of relational resilience with couple burnout and spousal support in families with a disabled child. *The Family Journal, 25*(4), 407–13. https://doi.org/10.1177/1066480717731215

Bayat, M. (2007). Evidence of resilience in families of children with autism. *Journal of Intellectual Disability Research, 51*(9), 702–714. https://doi.org/10.1111/j.1365-2788.2007.00960.x

Benson, P. R., & Karlof, K. L. (2009). Anger, stress proliferation, and depressed mood among parents of children with ASD: A longitudinal replication. *Journal of Autism and Developmental Disorders, 39*(2), 350–362. https://doi.org/10.1007/s10803-008-0632-0

Boyd, B. A. (2002). Examining the relationship between stress and lack of social support in mothers of children with autism. *Focus on Autism and Other Developmental Disabilities, 17*(4), 208–215. https://doi.org/10.1177/10883576020170040301

Braun, V., & Clarke, V. (2006). Using thematic analysis in psychology. *Qualitative Research in Psychology, 3*(2), 77–101. https://doi.org/10.1191/1478088706qp063oa

Brown, H. K., Ouellette-Kuntz, H., Hunter, D., Kelley, E., & Cobigo, V. (2012). Unmet needs of families of school-aged children with an autism spectrum disorder. *Journal of Applied Research in Intellectual Disabilities, 25*(6), 497–508. https://doi.org/10.1111/j.1468-3148.2012.00692.x

Cobb, S. (1976). Social support as a moderator of life stress. *Psychosomatic Medicine, 38*(5), 300–314. https://doi.org/10.1097/00006842-197609000-00003

Derguy, C., Michel, G., M'bailara, K., Roux, S., & Bouvard, M. (2015). Assessing needs in parents of children with autism spectrum disorder: A crucial preliminary step to target relevant issues for support programs. *Journal of Intellectual and Developmental Disability, 40*(2), 156–166. https://doi.org/10.3109/13668250.2015.1023707

Desmarais, K., Barker, E., & Gouin, J. P. (2018). Service access to reduce parenting stress in parents of children with autism spectrum disorders. *Current Developmental Disorders Reports, 5*(2), 116–123. https://doi.org/10.1007/s40474-018-0140-7

Dunst, C. J., Trivette, C. M., & Hamby, D. W. (2006). *Technical manual for measuring and evaluating family support program quality and benefits.* Winterberry Press. http://library.bsl.org.au/jspui/bitstream/1/4994/1/DunstC_Technical-manual-for-measuring-and-evaulating_Winterberry-2006.pdf

Ekas, N. V., Lickenbrock, D. M., & Whitman, T. L. (2010). Optimism, social support, and well-being in mothers of children with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 40*(10), 1274–1284. https://doi.org/10.1007/s10803-010-0986-y

Freedman, R. I., Litchfield, L. C., & Warfield, M. E. (1995). Balancing work and family: Perspectives of parents of children with developmental disabilities. *Families in Society, 76*(8), 507–514. https://doi.org/10.1177/104438949507600807

Galpin, J., Barratt, P., Ashcroft, E., Greathead, S., Kenny, L., & Pellicano, E. (2018). 'The dots just don't join up': Understanding the support needs of families of children on the autism spectrum. *Autism, 22*(5), 571–584. https://doi.org/10.1177/1362361316687989

Government of Ontario. (2019). *Ontario Autism Program.* https://www.ontario.ca/page/ontario-autism-program

Government of Ontario. (2021). *Ontario Autism Program news and program updates.* https://www.ontario.ca/page/ontario-autism-program-news-and-program-updates

Hartley, S. L., & Schultz, H. M. (2015). Support needs of fathers and mothers of children and adolescents with autism spectrum disorder. *Journal of Autism and Developmental Disorders, 45*(6), 1636–1648. https://doi.org/10.1007/s10803-014-2318-0

Hoogsteen, L., & Woodgate, R. L. (2013). Centering autism within the family: A qualitative approach to autism and the family. *Journal of Pediatric Nursing, 28*(2), 135–140. https://doi.org/10.1016/j.pedn.2012.06.002

Jones, J., & Passey, J. (2004). Family adaptation, coping and resources: Parents of children with developmental disabilities and behaviour problems. *Journal on Developmental Disabilities, 11*(1), 31–46. https://oadd.org/wp-content/uploads/2016/12/jonespassey.pdf

Kazak, A. E., & Wilcox, B. L. (1984). The structure and function of social support networks in families with handicapped children. *American Journal of Community Psychology, 12*(6), 645–661. https://doi.org/10.1007/BF00922617

Luther, E. H., Canham, D. L., & Cureton, V. Y. (2005). Coping and social support for parents of children with autism. *The Journal of School Nursing, 21*(1), 40–47. https://doi.org/10.1177/10598405050210010901

Mackintosh, V. H., Myers, B. J., & Goin-Kochel, R. P. (2005). Sources of information and support used by parents of children with autism spectrum disorders. *Journal on Developmental Disabilities, 12*(1), 41–51. https://www.researchgate.net/publication/263965939_Sources_of_information_and_support_used_by_parents_of_children_with_autism_spectrum_disorders

Meadan, H., Halle, J. W., & Ebata, A. T. (2010). Families with children who have autism spectrum disorders: Stress and support. *Exceptional Children, 77*(1), 7–36. https://doi.org/10.1177/001440291007700101

Rivard, M., Lépine, A., Mercier, C., & Morin, M. (2015). Quality determinants of services for parents of young children with autism spectrum disorders. *Journal of Child and Family Studies, 24*(8), 2388–2397. https://doi.org/10.1007/s10826-014-0041-2

Siklos, S., & Kerns, K. A. (2006). Assessing need for social support in parents of children with autism and down syndrome. *Journal of Autism and Developmental Disorders, 36*(7), 921–933. https://doi.org/10.1007/s10803-006-0129-7

Stahmer, A. C., Vejnoska, S., Iadarola, S., Straiton, D., Segovia, F. R., Luelmo, P., Morgan, E. H., Lee, H. S., Javed, A., Bronstein, B., Hochheimer, S., Cho, E., Aranbarri, A., Mandell, D., Hassrick, E. M., Smith, T., & Kasari, C. (2019). Caregiver voices: Cross-cultural input on improving access to autism services. *Journal of Racial and Ethnic Health Disparities, 6*(4), 752–773. https://doi.org/10.1007/s40615-019-00575-y

Volden, J., Duku, E., Shepherd, C., Georgiades, S., Bennett, T., Di Rezze, B., Szatmari, P., Bryson, S., Fombonne, E., Mirenda, P., Roberts, W., Smith, I., Vaillancourt, T., Waddell, C., Zwaigenbaum, L., & Elsabbagh, M. (2015). Service utilization in a sample of preschool children with autism spectrum disorder: A Canadian snapshot. *Paediatrics & Child Health, 20*(8), e43–e47. https://doi.org/10.1093/pch/20.8.e43.

Whiting, M., Nash, A. S., Kendall, S., & Roberts, S. A. (2019). Enhancing resilience and self-efficacy in the parents of children with disabilities and complex health needs. *Primary Health Care Research & Development, 20*(e33), 1–7. https://doi.org/10.1017/S1463423619000112

Woodgate, R. L., Ateah, C., & Secco, L. (2008). Living in a world of our own: The experience of parents who have a child with autism. *Qualitative Health Research, 18*(8), 1075–1083. https://doi.org/10.1177/1049732308320112.