**Understanding How Parents of Children with Autism Spectrum Disorders
Perceive the Role of Formal and Informal Support Resources**

by

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ABSTRACT

UNDERSTANDING HOW PARENTS OF CHILDREN WITH AUTISM SPECTRUM
DISORDERS PERCEIVE THE ROLE OF FORMAL AND INFORMAL SUPPORT
RESOURCES

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The purpose of this study was to understand the influence of support resources on the lives of

parents of children with Autism Spectrum Disorder (ASD). A family-systems approach was

adopted to examine how parents perceive the Ontario Autism Program (OAP) to be effective in

supporting their needs and the impact of COVID-19 on accessing support. This study followed a

mixed-methods approach, whereby 35 participants completed an online survey. Descriptive

statistics were collected to create a demographic profile of the sample population and thematic

analysis was used to provide detailed experiences of parents who access support resources for

their families. Participants identified several barriers to accessing services, such as funding

restrictions and lengthy waitlists; additionally, parents indicated that services did not consider the

needs of the entire family unit. The thesis concludes with recommendations for key stakeholders

to improve the centralization and coordination of services to help ameliorate barriers faced by

families.

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Introduction

Autism Spectrum Disorder (ASD) is a developmental disorder that affects the development of social communication and behaviours. It is characterized by: "persistent deficits in social communication and interactions" and "restricted, repetitive patterns of behavior, interests, or activities," as outlined in the fifth edition of the Diagnostic and Statistical Manual of Mental Disorders (DSM-5; American Psychiatric Association, 2013, p. 31). The DSM-5 consolidated autistic disorder, Asperger's disorder, and pervasive developmental disorder into a single ASD diagnosis to represent a continuum of symptoms (American Psychiatric Association, 2013; Wiggins et al., 2019). For this paper—and in alignment with previous research—these developmental disorders will continue to be included in the broader discussion of ASD.[1]

The onset of ASD symptoms most often occurs during late infancy, but some children may not display symptoms until the age of 2 (Woodgate et al., 2008). Characteristics of ASD are typically detected in early childhood, with males being four times more frequently diagnosed than girls in Canada (Ofner et al., 2018). Among those diagnosed by the age of 17, 56% have received a diagnosis before turning 6 years old—data suggests that treatment and interventions are most effective when the child is diagnosed before turning 5 years old (Woodgate et al., 2008). In Canada, it was reported that among children and youth between the ages of 5 and 17, 1 in 66 is diagnosed with ASD (Ofner et al., 2018). The focal population of the current study was parents of children between the ages of 6 and 17. This age group was of interest due to the current Ontario Autism Program (OAP) guidelines and funding eligibility criteria (Government of Ontario, 2019a). The OAP focuses its funding efforts extensively on children 6 years old and

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[1] This thesis uses the term ASD, as well as person-first language throughout (i.e., "children with autism"). In doing so, I acknowledge the complexities behind ASD and recognize the importance of identity-first language for the Autistic community (see Gernsbacher, 2017).

under, with these children receiving a majority of the available funding. Families with children under the age of 6 are currently eligible to receive up to $20,000 annually, while families with a child over the age of 6 are only eligible for up to $5,000 annually (Government of Ontario, 2019a). As of March 2021, the government of Ontario announced that they would be launching core clinical services for 600 children as a step towards developing a needs-based ASD program (Government of Ontario, 2021). The services will be delivered through a determination of needs process that includes meeting with families to identify the child's goals, strengths, and needs and allocating funding to purchase clinical services (Government of Ontario, 2021). The government determined that children would be eligible to receive funding based on their identified support needs but plans to allocate this money based on age. This research aims to shift the focus to families of children aged 6 to 17 who receive less funding and support, to understand the impact of service accessibility and availability.

Due to the all-encompassing nature of ASD, previous researchers have reported that the mental health of family members is directly affected by the child's ASD (Benson & Karlof, 2009; Cridland et al., 2014). The significant challenges associated with parents receiving a diagnosis of ASD for their child was the focus of several studies over the last decade (e.g., Benson & Karlof, 2009; Gray, 2006; Lee, 2009; Luther et al., 2005; Mandell & Salzer, 2007; Meadan et al., 2010; Nealy et al., 2012). These challenges include financial difficulties (Vohra et al., 2014), a sense of loss and depression (Nealy et al., 2012), poor mental health (Meadan et al., 2010), changes in relationships, and personal or professional sacrifices (Nealy et al., 2012). When asked about the overall impact of parenting a child with ASD, Nealy et al. (2002) reported that the theme of emotional impacts was most frequent. Parents[2] raising a child with ASD—

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[2] "Parents" will be employed throughout this thesis to reference "parents of children with Autism Spectrum Disorder."

particularly mothers—experience higher levels of anger and depressed mood (Benson & Karlof, 2009; Weiss, 2002). Mental health factors such as anger, depression, and anxiety have been found to subsequently affect levels of distress among parents (Benson & Karlof, 2009). The most stressful factors for mothers are concern over the permanency of ASD, poor acceptance by society, and low levels of social support (Boyd, 2002). Mothers also report performing more childcare, home maintenance, and collaboration with professionals than fathers, thus contributing to their stress levels. However, studies have shown that fathers were as likely as mothers to reference stress, without mention of child-specific characteristics that contribute to the development of stress (Alves & Maich, 2019). These findings indicate that parents' perception of societal factors—including lack of resources or social isolation—may be contributing to stress rather than child-specific characteristics. Luther et al. (2005) reported that parenting a child with ASD can be more stressful than parenting a child with a chronic illness and is a precipitating factor in parental depression. Despite these variables, many parents generally perceive themselves as capable and effective in the parenting role (Galpin et al., 2018). Parents who felt effective in the parenting role and reported a positive perception of parental self-efficacy also rated themselves as having better mental health (Galpin et al., 2018). However, these feelings were only present when parents viewed their important support needs as being met (Galpin et al., 2018; Hartley & Schultz, 2015; Jones & Passey, 2004). Parents who valued positive coping and social support adapted successfully to parenting a child with ASD and experienced family cohesiveness (Jones & Passey, 2004). Parents can readily develop and employ well-functioning coping strategies when they feel that crisis-meeting support resources meet the demands of their adverse circumstances (Weiss, 2002).

The ability to successfully adapt to supporting a child with ASD is mediated by the psychosocial resources available that allow parents to cope more effectively with adversity (Benson & Karlof, 2009). Several studies have approached the topic of coping strategies and social support for parents of children with ASD (e.g., Dunn et al., 2001; Gray, 2006; Jones & Passey, 2004; Lee, 2009). Coping strategies involve the maintenance of family integration and cooperation, active and external strategies, and ignoring or avoidance (Jones & Passey, 2004). While these studies have reported that positive coping and support can mediate the increased risk of negative psychological outcomes, they also frame the child with ASD as a stressor to family life. ASD has been described as "[one of the] most stressful of childhood developmental disabilities" (Gray, 2006, p. 970), with few disorders posing a "greater threat to the psychosocial well-being of parents" (Gray & Holden, 1992, p. 83). Research that frames parental well-being and adversity as directly attributed to the child's ASD does not consider family experiences through the life cycle or the direct and indirect ways that families experience ASD. It is important to note that research that understands ASD as a stressor to family life is viewed from a deficit-based theory, and primarily the medical model perspective. The medical model dehumanizes, pathologizes, and alienates the Autistic community by hyper-focusing on a deficit-view of ASD—over-focusing on what the person cannot do instead of what they can do (Anderson-Chavarria, 2021). A medical conceptualization of ASD may negatively impact agency and identity while continuing to define individuals by their diagnosis and perceived deficits. Researchers should instead allow for "nuance, complexity, and individualized experiences" when understanding neurodiversity (Anderson-Chavarria, 2021, p. 14).

It is important to recognize that families do not experience disability in the same way. In fact, many parents do not view their child's ASD as a burden (Brown et al., 2011). Stress is often

examined in a fragmented manner, whereby the broad range of contributing factors, such as the dispersion of responsibilities and boundaries of family life, are rarely considered (Cridland et al., 2014). Stress is not only developed from sources within the family, but also external sources, such as through a lack of appropriate local services, a lack of sufficient special education, and a limited knowledge of the service system (Sivberg, 2002). The dominant discourse within ASD research focuses heavily on the challenges and difficulties faced by parents. While this model highlights sources of stress, it does not effectively represent the parent-child relationship as a reciprocal and bidirectional interaction. For this reason, the current study looked at the family unit within the framework of family systems theory. Extending the focus beyond the immediate family to include informal and formal support networks allowed for a better understanding of the resources associated with family adaption to ASD. A comprehensive understanding of the family warrants an investigation of the support mechanisms that parents utilize (Cridland et al., 2014); this approach is further discussed and expanded upon in the theoretical frameworks section.

Social support, as defined by Cobb (1976), is "information that makes individuals believe [they] are receiving care and love, and that [they] are valued and esteemed; social support plays an important role in a network of mutual obligation and communication" (p. 300). Social support is a multidimensional construct that involves instrumental, informational, financial, and practical support—encompassing both formal and informal resources. These support resources are associated with family adaption to parenting a child with ASD and extend beyond the immediate family to include formal and informal social networks. Formal support can refer to the services received from professional-based organizations (Boyd, 2002), government-funded programs (Galpin et al., 2018), respite care services (Papageorgiou &Kalyva, 2010), and community or recreational programs (Siklos & Kerns, 2006). Such formal support services can play an

important role in providing information, increasing parent training and education, and relieving daily demands (Renty & Roeyers, 2006). Informal supports include the wide array of advice, assistance, encouragement, understanding, and sympathy received from others (Hartley & Schultz, 2015). Parents receive this support from their spouse, extended family, friends, other parents of children with ASD, religious groups, and support groups (Papageorgiou & Kalyva, 2010). The role of formal support has less significance in reducing stress for parents than informal support from personal social networks (Renty & Roeyers, 2006), but the combination of adequate professional support and informal support can be important for families (Renty & Roeyers, 2006). Informal support can be a powerful adjunctive resource, specifically in the form of parent support groups; these groups can be used alongside professional services to meet the needs of parents (Mandell & Salzer, 2007). Parents find value, belonging, and agency in participating in support groups and report an increase in parenting skills, a greater sense of emotional support, and a reduction in social isolation (Mandell & Salzer, 2007).

Alternatively, a lack of social support can negatively impact parental self-efficacy, decrease their ability to cope, and increase isolation. Kazak and Wilcox (1984) originally found that parents of children with disabilities use support services as much as other families but tend not to use them to a degree that is consistent with their needs. This finding was further supported by Rivard et al. (2015), who found that parents of children with ASD face greater challenges in obtaining support than parents with typically developing children—most notably due to the considerable effort required to find and gain access to specialized services. These findings highlight one of the gaps in knowledge that the current study explored. Several studies have researched support and coping strategies (e.g., Dunn et al., 2001; Gray, 2006; Jones & Passey, 2004; Luther et al., 2005; Sivberg, 2002), but largely overlook the role and meaning of supports

for parents, particularly in Canadian contexts. Kazak and Wilcox (1984) found that parents of children with special needs name fewer supports than parents of neurotypical children, but only indicated the quantity of supports rather than the quality of supports. Luther et al. (2005) and Meadan et al. (2010) discovered that parents who balance multiple roles assume large responsibilities of meeting the needs of their child, putting their own needs aside, and sacrificing time to seek out social support. While these studies examined social support and the impact of parental role responsibilities, they are American-based literature and underscore the lack of updated Canadian research.

It is important to consider the embeddedness of families within their social environment and how that environment can provide support to families (Kazak & Wilson, 1984). Seeking out support provides parents with a coping mechanism and allows for an increase in knowledge and control, but external barriers can limit parental support choices (Boyd, 2002). It is well-documented that families would benefit from increased social support, improved access to services, and a better understanding of child development (Ekas et al., 2010; Luther et al., 2005; Peck, 1998). The current research considers support resources beyond the immediate family to include the informal social network and formal resources associated with the perceived adequacy of support, rather than adopting a narrow developmental perspective that focuses on the intrinsic challenges related to a child's ASD. Sources of social support are instrumental for families of children with ASD, and it is through this research that we gain insight into the extent to which parents perceive resources to be effective in supporting their needs.

Review of the Literature

To date, literature on parents of children with ASD frequently examines these families in comparison to and with families of neurotypical children. This literature recognizes parents of

children with ASD as having experiences that differ in terms of where they seek out support, the importance of support, the development of multiple role responsibilities, and barriers to service access. Therefore, these topics will be addressed in the following section to provide context for the current thesis.

The Role of Social Support

Parental beliefs and perceptions about receiving adequate support for themselves are important predictors in adaption and coping (Siklos & Kerns, 2006). It is not just about the number of supports that parents receive, but the quality of support that plays an important role in maintaining family adaption, cohesiveness, and functioning. The benefit of social support stems primarily from perceived support: the extent to which parents regard themselves as being cared for and supported (Benson & Karlof, 2009). Weiss (2002) found that the perceived availability of social support is more important than the actual receipt of support for parents of children with ASD, as it enhances feelings of parental self-efficacy. With multiple outlets to seek out support, it is not surprising that there are various factors that moderate parents' use of support (Brown et al., 2011; Fisher et al., 1988; Moodie-Dyer et al., 2014). In general, individuals will employ a cost-benefit ratio of alternatives when dealing with challenging situations, either at a conscious, deliberate level or an emotional, reflexive level (Fisher et al., 1988). The benefits of seeking assistance can include improvements to one's emotional state or instrumental elements, whereas the costs often highlight one's feelings of inferiority and dependency (Fisher et al., 1988). The cost of seeking aid can be applied to parents of children with ASD, whereby seeking support from within and outside of one's social network involves both costs and benefits. Parents feel more comfortable receiving aid from their immediate social networks, such as friends and family, without feeling immediately obligated to reciprocate (Fisher et al., 1988). Kazak and

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Wilcox (1984) found that parents of children with ASD overload their immediate networks with requests for help because the costs associated with unreciprocated aid are fewer with family. This is further supported by Weiss's (2002) findings, whereby mothers of children with ASD perceived aid from immediate family members to be the most helpful in meeting their support needs. Although parents of children with ASD name fewer people who support them, these findings only highlight the number of available helpers and do not indicate the quality of support.

In general, informal support sources are more effective and beneficial for parents—particularly mothers (Boyd, 2002; Bromley et al., 2004; Galpin et al., 2018). Research results have indicated that mothers first turn to their spouses as a form of social support (Boyd, 2002; Ekas et al., 2010). While parents do not expect support to solely come from their spouse or partner, mothers emphasize the benefits of spousal support and the importance of their parental role. Spousal support is a protective factor that can increase harmony within the family, strengthens communication, mediates the impact of adverse events, and can increase the quality of support provided to the child (Aydogan & Kizildag, 2017). Parents in Tunali and Power's (2002) study reported that having a child with ASD has resulted in higher levels of spousal support, making it likely that parents are more comfortable relying on each other rather than discussing private family information with unfamiliar sources. Despite placing more emphasis on spousal support, spouses may not always be the best source of support as they can be equally distressed and unable to provide effective support. Hartley and Schultz (2015) reported that, when partners had relatively high levels of unmet support needs, so did their spouse. However, the maternal perspective is dominant in ASD discourse, with mothers reporting a higher number of support needs than fathers (Hartley & Schultz, 2015). The difference in support needs reflects a greater role in caregiving in that role specialization often occurs in families with children with

ASD. Role specialization refers to mothers who take on more childcare responsibilities and fathers who take on more paid employment as a response to the nature of caregiving (Hartley et al., 2014). Hartley et al. (2014) suggest that there is a shift toward role specialization "during the transition to parenthood that lasts through [childhood], the period in which childcare demands are highest" (p. 628). The current study considered the multiple and varied roles that parents undertake and the influence of this from both a maternal and paternal perspective.

The association between informal support and maternal well-being is consistent throughout multiple studies (Boyd, 2002; Bromley et al., 2004; Galpin et al., 2018); however, Dunn et al. (2001) cited no direct relationship between social support and feelings of isolation. In fact, parents felt isolated despite receiving some level of support, with isolation being the result of external sources such as a lack of societal understanding (Woodgate et al., 2008). The role of formal support from professionals and government-funded programs has less significance to parents, mainly due to the perception that these supports are not tuned to their needs (Renty & Roeyers, 2006). Professionals can play an important role in helping and supporting families, but it is of utmost importance that they meet the specific support needs of parents. Agosta (1989) discussed that professional services should embody the following fundamentals to adequately support parents: enabling and empowering parents and being open, flexible, and accommodating to familial needs (p. 5). Nevertheless, parents report that the services available are not living up to these basic principles (Siklos & Kerns, 2006). Professional support, in concordance with informal support networks, is important in helping parents navigate their caregiving responsibilities and must be designed to proactively support families' needs.

Beginning in the pre-diagnostic stage, parents experience caring for a child with ASD and understand how to respond at each developmental stage (Depape & Lindsay, 2015). Depape and

Lindsay (2015) outlined parents' experiences with ASD, which included six stages: pre-diagnosis, diagnosis, family life adjustment, navigating the system, parental empowerment, and moving forward (p. 572). Parents can experience these stages in sequential order, but it is not uncommon for stages to occur later, not at all, or for parents to cycle backwards to re-experience a stage. Throughout these stages, parents experience an array of emotions associated with family life adjustment and navigating their "new normal" (Depape & Lindsay, 2015; Woodgate et al., 2008). In learning to understand ASD, parents often experience feelings of isolation and stigmatization from both their inner social network and broader society. Woodgate et al. (2008) found that parents ultimately felt that they were living in a world of their own; one that left them feeling isolated. Parents' sense of isolation arises from different sources such as society's lack of understanding, a disconnect from family and friends, and an unsupportive service system (Woodgate et al., 2008). These findings are not surprising, as decreasing social support is shown to correspond to the likelihood that external stressors will increase isolation (Dunn et al., 2001). A lack of support can increase alienation and decrease parents' perceived ability to successfully cope and adapt. Furthermore, parents often experience concern over the unpredictable and socially unacceptable behaviours of their child, thus restricting activities outside of the home and decreasing opportunities for social support (Nealy et al., 2012). Parents place their necessities aside and put more energy into ensuring their child's needs are met, sacrificing a part of themselves (Hoogsteen & Woodgate, 2013). Over time, parents learn how to take breaks and seek out support, but there is an overwhelming number of parents who still feel isolated, unheard, and unsupported. Isolation and alienation often culminate due to a lack of understanding of ASD and the adversarial nature of support services (Galpin et al., 2018). Parents in Galpin et al.'s (2018) study described the adversarial nature of support services as

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having to repeatedly battle for information and push for accessible supports, which ultimately comes down to "who is more able and who [can] shout the loudest [to be] heard" (p. 577). Existing support services, particularly formal services, are often found to not fit with individual family needs and lack whole-family support (Galpin et al., 2018). Current services do not utilize a family-focused approach, whereby services are extended beyond the child to include those with whom the child interacts regularly. Support resources should strive to increase family adaptability, normalization, and assist in securing both social networks and professional assistance (Peck, 1998).

The benefits of using a family-centred approach to professional and formal services in increasing adaptability and cohesiveness within the family have been the focus of multiple studies (Farrell & Barnes, 1993; Hartley & Schultz, 2015; Woodgate et al., 2008). Adaptability is the degree to which the family power structure, roles, and rules of communication are rigid or changeable; cohesion refers to the level of bonding and degree of autonomy within the family (Farrell & Barnes, 1993). These concepts are related to one another such that, as adaption increases, the cohesiveness and functionality of the family structure also increase. Previous research has revealed that families of children with disabilities experience various physical, emotional, and social impacts when coping with and adapting to day-to-day living (Bayat, 2007; Whiting et al., 2019). Some parents cope more effectively in their new role, which is attributed to resilience and the ability to bounce back in the face of adversity (Whiting et al., 2019). Several attributes of resilience have been identified, such as the ability to manage emotions, self-efficacy, coping strategies and external sources of support. Whiting et al. (2019) found that parents perceived engagement with informal and formal sources to be positive, but the lack of availability presented challenges to maintaining resilience. Making meaning out of adversity has

been cited as a key process in family resilience (Bayat, 2007); however, this can be particularly difficult for parents to achieve due to the actualities of support services. These supports often do not consider the tenets of family-centred care and the support needs of parents go unmet (Hartley & Schultz, 2015). The difficulties faced when obtaining services or gaining accessible and understandable information is one of the most significant challenges for parents. The *unsupportive system,* as described by many parents, is manifested by the inaccessibility of information and limited, inadequate, or inappropriate resources (Woodgate et al., 2008). As a result, parents are forced to adopt multiple roles and assume responsibility for learning, educating, and supporting their families.

Development of Overlapping Roles

Social support networks play an important role in parental functioning and coping but have also been examined to mediate the stress associated with balancing multiple roles (e.g., Hartley et al., 2014; Hartley & Schultz, 2015; Morgan, 1988). With family life revolving around the child with ASD, interactions inside and outside of the family are altered to accommodate the child's needs (Morgan, 1988). Parents then find themselves balancing multiple role responsibilities and frequently experience role strain (Hall et al., 2016). Role strain, as defined within role theory, is expanded upon later in the theoretical frameworks section of this thesis. Typically, mothers have reported a higher number of unmet support needs, which may reflect a greater role in caregiving (Hartley & Schultz, 2015). Mothers often assume primary responsibility for tasks associated with the management of the child's everyday life, thus contributing to difficulties fulfilling multiple role obligations. Alternatively, fathers often report their support needs as being met, which could translate into less involvement in services as compared to mothers and more attention to time spent in paid employment (Hartley et al., 2014;

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Hartley & Schultz, 2015). This role specialization thus contributes to role strain and variations in social support needs. The extent to which mother-father differences in caregiving are noticeable or genuinely experienced has produced varying research results (Hartley et al., 2014; Hickey et al., 2018). Some mothers may be aware of this difference but are content with the unequal distribution of caregiving, whereas others may accept the increase in role demands because it meets their family's needs but are not ultimately satisfied (Hickey et al., 2018; Maich et al., 2019). When undertaking multiple roles, mothers reported benefitting from assistance with accessing childcare, help around the house, and involvement in support groups, while fathers reported benefitting from increased opportunities for self-care (Hartley & Schultz, 2015). These findings highlight the inconsistencies among role responsibilities within families with children with ASD.

The continuity of support and access to coordinated care are highlighted as major issues for parents (Brown et al., 2012). Parents often cite themselves as the main case manager for their child; in fact, 89% of parents in one study reported themselves as such (McLennan et al., 2008). Parents are responsible for navigating the educational, social service, and health care systems to access services for their children (Desmarais et al., 2018). The role strain that occurs within these families reflects the development of overlapping roles (Hall et al., 2016; Hartley & Schultz, 2015; Hoogsteen & Woodgate, 2013). Parents attained multiple roles at home and in the community, including that of an advocator, organizer, tutor, educator, and caregiver. They spend numerous hours helping their child cope and adapt, advocating for their child, and learning new skills. One of the key roles that parents take on is that of an educator or teacher (Hoogsteen & Woodgate, 2013). In their role as a teacher, parents help educate their child and assist their child in relating to their external environment; further, they assume responsibility for learning and

teaching their child "ways of communication and roles of therapy when professional support [is]

lacking" (Hoogsteen & Woodgate, 2013, p. 137). Parents in this role educate themselves on

therapies, interventions, and services and are required to develop an intense knowledge base

about ASD. The discontinuity of supports for families is seen through a lack of funding for

private therapy, services that are cut at a certain age, and a lack of fit with the family (Brown et

al., 2012). When there is a lack of coordination among services for families with children with

ASD, there is an increase in concern over the quality and quantity of adequate, available

services. Participating in multiple roles takes a considerable amount of time, energy, and

patience from parents that leaves little time for themselves (Hoogsteen & Woodgate, 2013).

Acquiring new role responsibilities requires immense support for parents who leave their own

needs behind.

The time spent between multiple roles highlights the resources and support needed for

parents to care for both themselves and their child. Many parents use informal supports to assist

them while they balance multiple roles—both at work and at home. The needs of working

parents of children with ASD have shown to be similar to those of working parents without

children with ASD (Freedman et al., 1995; Watt & Wagner, 2013). Watt and Wagner (2013)

suggested that parents raising children with ASD self-report variables that are similar to parents

raising neurotypical children with respect to work interests, commitment, and quality of

employment. What distinguishes parents of children with ASD is the intensity and complexity of

arrangements that are required to successfully balance work and home responsibilities

(Freedman et al., 1995). Parents spend more time coordinating appropriate, professional services

and care for their child, which can be sporadic due to funding and the inability to maintain

trained professionals. Balancing work and family responsibilities can be challenging, as the

supports that parents construct are more fragile and tenuous than those of other families (Freedman et al., 1995).

Although not a focus of this research, it is worth mentioning the division of labour that exists within families with children with ASD. Previous researchers have reported on the rates at which women are employed while caregiving (e.g., Hartley et al., 2014), which is significantly less likely when compared against fathers. While mothers are more likely to take on the caregiving role, fathers are more likely to engage in paid work outside of the home. Furthermore, fathers may view employment as an escape from daily caregiving demands or as a coping outlet—fathers are much less likely to mention their child's diagnosis to coworkers and members outside of the home (Papageorgiou & Kalyva, 2010). The extent to which fathers withhold information about their child's ASD may predict whether they seek support from outside of their inner social network and are willing to share personal information. A high number of parents in Papageorgiou and Kalyva's (2010) study said that their colleagues accepted their child with ASD and offered support in the form of job flexibility and employee benefits; yet, more than one-third of parents did not inform their colleagues of their child's ASD citing a desire to avoid pity and misunderstandings, as well as being afraid of stigmatization and invasions of privacy. Notably, more fathers than mothers withhold from their colleagues that they had a child with ASD and subsequently, report a greater lack of understanding and support from outside of the home (Papageorgiou & Kalyva, 2010). Fathers may be more concerned about stigmatization and the negative influence it could have on acquiring equal opportunities for promotion (Papageorgiou & Kalyva, 2010). They are actively hiding a large part of their lives from those whom they interact with daily, which can cause greater role strain and exacerbate support needs. Work can play a vital and positive role in increasing support for parents, but the development of overlapping roles

can contribute to strain, overload, and conflicts. For parents to be adequately supported, numerous outsiders need to become involved and familiar with the family (Major, 2003). Parents must recognize the resources and barriers afforded by existing roles—securing sources of instrumental support, identifying emotional and social support, and considering resources within the workplace, community, and from friends or family (Major, 2003). Although several potential sources of support exist, researchers have found that parents of children with ASD perceive relatively less social support and experience limited accessibility and availability of resources (Alves & Maich, 2019; Major, 2003; Vohra et al., 2014; Weiss et al., 2016). Balancing multiple role responsibilities is difficult and not all parents will enact roles in the same way, but services must consider the current and future needs of families to make meaning out of adversity and successfully support them through the parenting process.

Unmet Needs and Barriers to Service Access

The organization of ASD funding and service delivery for children with ASD in Canada varies depending on province or territory (Brown et al., 2012). Current policies affect the services that children and parents receive, outlining the need to better understand the factors related to service selection and acquisition. Currently, the Ontario Autism Program is an age- and income-based program with services geared towards children and youth under the age of 18. Nevertheless, there is an identified lack of Ontario-based ASD-focused research, with service delivery in Canada described as overburdened (Brown et al., 2012). Brown et al. (2012) found that the unmet support needs of parents could be attributed to and a direct reflection of a service system that "has difficulty keeping pace with the demands placed upon it" (p. 506). While Canada has seen a growing awareness of and improvement in services due to successful parental advocacy (Volden et al., 2015), inconsistencies in access to support continue to exist.

Recently, researchers have reported on the specific areas of support needs for parents of children with ASD (e.g., Derguy et al., 2015; Hartley & Schultz, 2015). These analyses showed that mothers and fathers discussed similar support needs with this overlap reflecting the family-wide impacts of ASD, the need for education about ASD, and a desire for partnership with professional services (Hartley & Schultz, 2015). Additionally, parents expressed a need for information, materials, guidance, daily management, relational support, and emotional support (Derguy et al., 2015). This extensive list of important support needs highlights the difficulties faced when accessing formal and informal services and underlines the need for support from professionals. Having the knowledge and skills related to ASD does not seem to be enough for parents to feel sufficiently supported in the parenting role (Derguy et al., 2015). To increase parental self-efficacy, social and institutional networks are essential pillars that provide an educational and emotional framework that allows social isolation to be broken down. Parents have expressed the need for support but continue to perceive the service system as unsupportive, inaccessible, unavailable, and most commonly, passive rather than active (Alves & Maich, 2019; Brown et al., 2012; Stahmer et al., 2019; Woodgate et al., 2008).

The primary challenge for the service delivery system is ensuring that families with children with ASD receive interventions and support based on their unique needs (Moodie-Dyer et al., 2014). Systemic characteristics that promote or obstruct service use—affordability, availability, and accessibility—are extremely important when determining parents' perception of social support (Weiss et al., 2016). The brunt of perceived systemic failures is borne by parents who already feel unsupported and access less social support (Galpin et al., 2018). These parents feel they do not have the same resources—time, money, energy, and opportunities—to engage with different types of support. Structural factors in the service system contribute to the

marginalization of families and disparities regarding access to and quality of care. It is often demographic factors such as race, income, and education that drive service utilization, rather than the equitable distribution of support services based on need (Stahmer et al., 2019). Service provision varies considerably across sites and over time, which continues to contribute to parents' perceptions of unmet needs. The Ontario Autism Program (OAP) guidelines discuss a plan based on principles of coordination and continuity of services, family-centred care, and evidence-based development (Government of Ontario, 2019a); yet parents discuss a distinct lack of resources available to address their specific support needs (Galpin et al., 2018). Improving the centralization and coordination of support services may help ameliorate the discontinuity that families continue to experience (Brown et al., 2012).

It is not surprising that a combination of formal and informal supports would help parents address their support needs. Relying on social support can help parents overcome feelings of inadequacy, isolation, and disconnect from society but gaps in the service system persist. The theme of service access and service delivery in the community emerged in Moodie-Dyer et al.'s (2014) study, with parents speaking of both positive and negative experiences. Positive experiences included having insider knowledge, communication, and lucky circumstances, while the negative experiences included delays in diagnosis, system disconnect, a lack of information, inadequate service providers, feeling devalued, and inconsistencies in service provision (Moodie-Dyer et al., 2014). Unfortunately, the negative experiences outweighed the positive experiences, highlighting the impact of the service system on families. The stress of service acquisition and maintenance, combined with barriers to accessing services, has the potential to culminate in perceived unmet support needs. The most frequently reported barriers to service access include financial costs, a complicated service system, a lack of family-centred services, limited cultural

awareness by providers, and a lack of information about services and funding (Brown et al., 2012; Derguy et al., 2015; Mackintosh et al., 2005; Stahmer et al., 2019; Woodgate et al., 2008). Families with children with ASD are at an increased risk for problems with access to care than their neurotypical counterparts, which can create additional financial and time constraints. Challenges in accessing ASD services are not experienced to the same altitude by all parents but are rather influenced by several factors (Pickard & Ingersoll, 2016). These barriers are especially predominant in underserved communities, such as racially and ethnically diverse groups, those of low socioeconomic status, those with limited English proficiency, and those with geographical limitations (Stahmer et al., 2019). Lower socioeconomic families may experience a greater number of structural and systemic barriers that impeded service access, including high service costs, transportation difficulties, and less awareness of available resources (Pickard & Ingersoll, 2016). Disparities in access are associated with lower income, more limited functional ability, and impacts to employment (e.g., cutting hours or stopping work altogether). This study did not specifically target responses from these communities, but it is important to recognize and understand their experiences and how their support needs may be exacerbated. Those delivering services need to be aware of parents that feel less able to engage or support themselves and their children when "[they are] confronted with a broad range of attitudinal and organizational barriers" (Weiss et al., 2016, p. 430). Mackintosh et al. (2005) found that parents relied on at least five to six different sources of support, differing by socioeconomic status and geographic location. Community and family factors, such as cultural differences, can act as barriers to service access and create difficult environments to promote authentic engagement within (Stahmer et al., 2019). It is crucial for those within the service system to consider and address the practical and logistical barriers that inhibit successful parental engagement in support services.

Systemic barriers to service access also contribute to disparities in accessible and equitable services and exacerbate unmet support needs for parents. The most common unmet needs reported by parents are a lack of informational resources, a lack of capacity and mandate for providers to equitably disseminate information, and limited advice or people to talk to (Stahmer et al., 2019). Parents experience significant difficulties navigating the service system and highlight the distinct lack of supports to address their needs (Brown et al., 2011; Moodie-Dyer et al., 2014; Pickard & Ingersoll, 2016). When support was available, it was perceived as difficult or impossible to access (Galpin et al., 2018). Parents experience limited understanding from others, isolation, a lack of support from professionals, and are continuously misunderstood or unheard (Jones & Passey, 2004). These experiences have culminated in frustration and confusion when attempting to navigate the service system and emphasize the need for case management by professionals. Due to the number of unmet support needs that parents experience, they often name fewer people who support them—their partner and immediate family are the most common sources (Boyd, 2002; Ekas et al., 2010; Jones & Passey, 2004). Personal relationships are a large source of support, whereas professional support is less likely to be viewed as helpful (Mackintosh et al., 2005). Siklos and Kerns (2006) reported that parents consistently endorsed needs related to professional agencies working with their families as being unmet. Parents perceived professional services as lacking information about services and funding (e.g., availability and eligibility) that create additional burdens for families, such as limited involvement in services and paying thousands in out-of-pocket expenses.

More recent research has shifted focus to the benefits of support groups and interacting with other parents of children with ASD to relieve unmet needs (e.g., Boyd, 2002; Depape & Lindsay, 2015; Hall et al., 2016; Mandell & Salzer, 2007). Support outside of the immediate

family can promote and support change, redefine adverse situations, and bring awareness to additional resources. Positive social impacts were noted to be most often formed through ASD support groups and 72% of parents in one study stated that their largest source of information was other parents (Mackintosh et al., 2005). It can be difficult for parents to find the time and identify the common interests necessary for friendship formation and maintenance, but these barriers are alleviated when interacting with similar others. Support groups can foster closeness and cohesiveness for parents, and work as a means of providing social support within the framework of a community setting (Luther et al., 2005). The support of other parents provides a safe place to discuss difficulties, share coping strategies, and gain knowledge. Other parents as a source of support surpassed using one's spouse, immediate friends and family, or professionals due to shared lived experiences (Mackintosh et al., 2005). Parents feel comfortable when discussing their feelings and experiences in a community that enables transparency and empowerment. Reliance on extensive, supportive social networks plays an important role in affecting parental well-being (Meadan et al., 2010). Those who use support networks and a variety of active coping strategies use positive framing as a vital means to understand adverse situations (Meadan et al., 2010); unfortunately, the ability to develop these networks and strategies do not apply to all parents seeking out support. Low income and racial minority families are at a greater disadvantage when receiving and accessing information and support. Factors such as financial, geographical, and structural restraints can create barriers for these parents (Mackintosh et al., 2005). Mandell and Salzer (2007) found that those using support groups were more likely to be "white, have an income of $40,000+, live in a suburban area, and be a college graduate" (p. 115). Support groups can be a great source of support but require a great deal of time and knowledge that some parents do not have. Access to support services is

not equally distributed across populations; minority communities and families of low socioeconomic status underutilize support when compared to those of middle- and upper-class families (Mandell & Salzer, 2007). The inconsistencies in access to support emphasize the primary challenge of the service delivery system to ensure that all families receive services based on their unique needs.

To assist parents appropriately, support should be given that allows parents to develop a greater sense of control, cohesion, and efficacy (Derguy et al., 2015). Formal support should take a "holistic approach that looks beyond the categorization of needs and allocation of resources based solely on the difficulties experienced by the child to [include] the perceived experiences of the family" (Galpin et al., 2018, p. 579). On average, parents report seven different sources of accessing information about ASD, representing the constant pursuit of information and support with which parents are sometimes consumed (Mackintosh et al., 2005). Professional support plays an important role in providing information, training parents, and developing linkages between families and services (Renty & Roeyers, 2006). It is important to modify formal support to the needs of families through the development of a parent-professional partnership. Given the crucial role that parents play in the lives of children with ASD across the lifespan, "it is imperative that [services] support the efforts of parents who care for their children" (Weiss et al., 2016, p. 431). Services and resources that aim to support parents and improve engagement with the service system must consider a host of factors—child and parent demographics, systemic barriers, and parents' perception of unmet support needs. Support resources are critical in providing parents with appropriate education, training, and assistance, making it necessary to understand the role that these resources play in parents' lives. Providing parents with basic psychoeducation, social support, and strategies to access services should be a critical aspect of

the diagnostic process and would serve to reduce frustration while enhancing integration and service knowledge (Pickard & Ingersoll, 2016).

Theoretical Framework

Disability literature and research are largely centred around discussions of children with Autism Spectrum Disorder as a stressor to family life. This dominant discourse embraces a narrow, developmental perceptive that ignores—and considers unimportant—the total family system (Cridland et al., 2014; Morgan, 1988). While this model has previously highlighted sources of stress for parents and the effects of ASD on family functioning, it leaves little room for assessment of the family structure and the impact of various components on overall adaption and cohesion. This representation of families with children with ASD does not consider the diversity and social interactions embedded within each family system. The current study utilized the frameworks of Family Systems Theory and Role Theory, as touched upon in the previous literature review. The combination of these theories allowed for a deeper understanding of the role and meaning of support resources for parents while considering the bidirectional parent-child relationship. In employing both Family Systems Theory and Role Theory, it was important that this research allowed space for both maternal and paternal perspectives. As can be seen from previous literature, ASD research has highlighted the importance of the maternal perspective and the association between social support and maternal well-being, due to their greater role in childcare (Bromley et al., 2014; Hartley & Schultz, 2015). The current study aimed to give both mothers and fathers a prominent voice in ASD research by focusing on their experiences in seeking social support. An exploration of parents' self-reported needs and perceptions of the service system is required to comprehend the role and meaning of support resources for parents.

Family Systems Theory

Family Systems Theory (FST) describes the individuals that a family relies on for comfort, care, and support while considering the complex interplay of various elements, such as "emotional closeness, cognitive engagement, and social connectedness and communication" (Cridland et al, 2014, p. 216). This approach focuses on both the family system in relation to other systems—other families, school, and social groups—and the subsystems within the family, including maternal, paternal, marital, and sibling relationships. Research encompassing a family systems approach provides better insight into the family dynamic and allows for a more realistic view that stresses the interaction between the child's development and the complex system within which they function (Morgan, 1988; Prendeville & Kinsella, 2019). Children with ASD are embedded within multiple systems which interact in direct and indirect ways—the most important system being the family, but the influence of extended family, friends, school, and the service system are not ignored. Family systems research captures the heterogeneity of families and considers the interactions between these multiple systems (Prendeville & Kinsella, 2019). A comprehensive understanding of family life involves a critical examination of the support resources that parents utilize and the role that they play. Cridland et al. (2014) suggest that mothers and fathers differ in both the types of support they provide to families and the support that they receive from outside of the family. It is not enough to look at the relationships within the family but to also understand the influences of other systems, such as the community, social groups, and professionals. Researchers need to examine the unique support needs of families and the role that supports play in impacting the family subsystem. FST encourages inclusive and flexible approaches to ASD research that includes those outside the traditional scope of the family structure. The utilization of FST in examining the role and meaning of support resources

for parents ensures that family functioning is recognized across time and in response to different life events (Cridland et al., 2014). To understand the different experiences of family members, researchers have examined the relationship between parental stress and the child's ASD, as well as between stress and support systems (Boyd, 2002; Gray & Holden, 1992; Jones & Passey, 2004; Mandell & Salzer, 2007; Meadan et al., 2010). To date, these research studies consider the child as a source of stress to parental well-being and describe only a unidirectional parent-child relationship; however, the family system and patterns of interaction can only be fully understood when a bidirectional focus is employed. In using a family-focused approach, the current study examined the embeddedness of parents within multiple systems and moves beyond a reliance on the developmental perspective of ASD as a stressor.

Role Theory

Role Theory, as described by Major (2003), is "concerned with the study of behaviours that are characteristic of persons within contexts and with various processes that presumably produce, explain, or are affected by those behaviours" (p. 47). In the context of families with children with ASD, the focus is on the roles—or expected set of behaviours—that are associated with being a parent. The role of *parent* is accompanied by certain behavioural expectations from the social system in which they are embedded (Major, 2003). Roles can become personalized, as not all parents are subject to identical experiences and will not enact the parental role in the same way. Major (2003) describes the importance of role negotiation, which is defined as the process whereby roles develop. Role negotiation emphasizes role development as involving more than one focal person through collaboration. Within this framework, roles are dynamic and can be renegotiated as circumstances change (Major, 2003). Role theory helps in understanding how parenting roles can change across time and vary depending on demographic contexts. Major's

(2003) study examined families with children with chronic illnesses, but the tenets of role theory are applicable across contexts. Understanding roles as dynamic is particularly important for families with children with ASD, as renegotiations often need to be made in accordance with changes to the child's health or developmental transitions.

For adequate care to be provided to the family, numerous outsiders need to become involved and familiar with the family (Morgan, 1988). Parents often need to consider the features of ASD that create individual role demands—severity, predictability, and communicability (Morgan, 1988). Identifying caregiver role demands helps parents understand their current needs and anticipate future needs. Yet, along with identifying and defining role demands, parents must also recognize resources and sources of support that are available. As researchers have shown, parents take on multiple roles and place their necessities aside, making it difficult to seek out support (Hoogsteen & Woodgate, 2013). The demands of parenting can result in role strain or caregiver strain. Kirby et al. (2015) defines caregiver strain as the "demands, responsibilities, and difficulties of caring for a child" (p. 32). This definition is used throughout the current study to reference the experiences of strain for parents of children with ASD. It is important to understand which roles parents enact and how the development of overlapping roles impacts their ability to seek out social support. Parents of children with ASD are subject to different expectations when compared to parents of typically developing children and often experience barriers because of their existing roles (Major, 2003). The ability for parents to secure sources of instrumental, emotional, and practical supports is dependent on the demands of caregiver role sets. The current research study gains insight into the influential nature of the dynamic roles of parents.

Purpose and Objectives

The purpose of the current research was to assess the self-reported needs of parents of children with Autism Spectrum Disorder and understand how they perceive the role and availability of support resources. This information provided insight into the formal and informal supports that parents are utilizing and to what extent they are being utilized. By understanding the role that support resources play in parents' lives, the results of the current study can subsequently be used to understand parental knowledge of supports and their perceived need for these resources in their daily lives. In Canada, there is a growing awareness of the need to improve access to ASD support services, due to successful parental advocacy efforts and legal challenges (Volden et al., 2015). Many Canadian provinces and territories increased funding for ASD services, but each province developed its own approach (Volden et al., 2015). The Ontario government proposed improvements to the Ontario Autism Program in 2019, whereby a needs-based, sustainable program was being developed, but parents have yet to see this change enacted (Government of Ontario, 2019b). Starting in March 2021, around 600 children and youth across the province who are registered in the OAP will be participating in the program's launch of core clinical services, moving towards a needs-based program (Government of Ontario, 2021). Amid this provincial diversity, families continue to view support services as too limited and inaccessible, resulting in a lack of actual service utilization data (Volden et al., 2015). Through documenting parents' experiences, the goals of the current study were to document the utilization of support services and resources in Ontario and understand how changes to the OAP continue to impact families.

In recognizing the current global climate, this research also explored how the Coronavirus disease (COVID-19) continues to impact Ontarian families with children with ASD.

The disappearance of social networks, access to support resources, and opportunities to encourage community connections has the potential to exacerbate parents' unmet needs (McCue, 2020). Including specific questions about the pandemic allowed for a deeper understanding of the role that COVID-19 continues to play in the availability and effectiveness of ASD service delivery for families.

Research Questions

The research questions for this study were intentionally broad to account for the diversity and complexity of parent experiences:

Research Question #1: To what extent do parents perceive support resources to be effective in supporting their needs? To what extent do they perceive them as available and accessible?

Research Question #2: How have the recent changes to the Ontario Autism Program impacted parental perception of available and accessible supports?

Research Question #3: What role has COVID-19 played in the availability and effectiveness of service delivery?

With these research questions in mind, it was important to focus part of the current study on the impacts of the Coronavirus pandemic (COVID-19) for families of children with ASD. By including questions about COVID-19, the perceived availability of support following province-wide shutdowns could be understood. At the time of the survey, Ontario was under strict emergency orders that were extended into December, following the declaration of a second wave. The Ministry of Education released a guide to reopening Ontario schools, but the announcement was met with criticism, as advocacy groups worried that children with disabilities would face additional obstacles; parents were unsure if the school reopening plan would fully

and safely include their children (Waberi, 2020). The province's school system is designed primarily with non-disabled children in mind, leaving children with disabilities disproportionately affected by the pandemic (Waberi, 2020). Furthermore, this announcement came as parents were still juggling the economic, physical, and emotional demands of the pandemic. For children with ASD, who may be immunocompromised and vulnerable to the virus or have difficulty adapting to the health-related restrictions because of social or sensory challenges (e.g., wearing masks, temperature checks, and social distancing), the resumption of in-person learning was an increased risk. Consequently, many parents were forced to balance full-time caregiver, teacher, and work-related roles to meet the additional support needs of their children who could not go back to school (McCue, 2020; Rosen, 2020). As noted in previous literature, the development of multiple roles requires a great deal of time, effort, and knowledge from parents who sacrifice a part of themselves to provide for their child (Hoogsteen & Woodgate, 2013; Major, 2003). Parents assumed the responsibility of teaching their child and filling the gaps where support workers were no longer able to provide care. Obtaining multiple roles within and outside of the home has caused unmet needs to become exacerbated during the pandemic. The disappearance of support networks and opportunities to socialize added to the basic anxiety parents experience and is heightened by community shutdowns (McCue, 2020). The limits that were placed on community involvement and social interactions have increased feelings of isolation and stripped parents from a sense of normalcy (Viau, 2020).

Methodology

The following section outlines the methods for data collection and analysis in the current research study, including the characteristics of and inclusion criteria for the participants, the chosen research design, the procedures and instruments used, and the analysis process followed.

Participants

The participants of the current study were parents of children with a diagnosed Autism Spectrum Disorder—a diagnosis as per the current DSM-5 criteria. Researchers have suggested that parents accessing support services are likely to be white, well-educated, employed, and have a prominent voice in ASD research (Bromley et al., 2004; Brown et al., 2012; Mandell & Salzer, 2007). It was important to be cognizant of the systemic, financial, socioeconomic, and physical barriers that impact parents' abilities to seek out support resources and limit their involvement in ASD research. This research study aimed to be inclusive of all parental experiences, within the limits of the inclusion criteria, and recognize the need for underserved communities to have a voice in ASD research. This study was distributed solely online, with prospective participants invited to complete a survey on Qualtrics—an online survey provider—which may have disadvantaged those who do not have access to a computer or internet access; this limitation is discussed later in this thesis.

Inclusion Criteria

The inclusion criteria for this study were generally broad in scope. First and foremost, the survey was created with hopes that the experiences of both mothers and fathers would be included in this research. Previous research has focused solely on mothers, due to the notion that they are "most adversely affected by stress-related factors" (Boyd, 2002, p. 208), and role specialization (Hartley & Schultz, 2015). Although mothers may report a higher number of unmet support needs, fathers are at risk for having their support needs unmet, due to support services that are not designed to address broader paternal needs (Hartley & Schultz, 2015). This discrepancy made it increasingly important to address the mother-father differences in participation rates in ASD research. Parents had to be permanent residents of Ontario—parents

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did not have to originally be from Ontario, but it was pertinent that they currently resided in the province. Parents did not have to be married; this study included parents who were single, married, re-married, common-law, and/or adoptive or foster parents; however, this study did not apply to parents who were divorced and/or have their child with ASD in their care less than 50% of the time. The child with ASD must see the parents on a regular basis. Furthermore, the child had to be between 6 and 17 years old. As mentioned previously in this thesis, the OAP focuses its funding efforts extensively on children under the age of 6. This study instead focused on children above 6 years old to account for influencing factors—decreased funding and limited treatment options—that could lead to unmet support needs for parents. The OAP does not provide support for children once they turn 18, thus participants of this study had to have a child who had not turned 18.

Characteristics of Parents

The sample size for the current study included 35 participants[3]. This study collected characteristics for both the parents and their children, but it is to be noted that only parents completed this survey—child characteristics were filled out by the parents. Detailed characteristics for the final sample of parents are included in Table 1. A large majority of the population identified as female and most were White, married, employed, had completed some form of post-secondary education, lived in an urban location, and had one or two children. Participants had an average age of 40.1 years old (range: 31–50). There was a spread across reported yearly household income ranging from less than $20,000 to over $100,000. Finally, participants were asked information about how many children they had and how many had been diagnosed with ASD—participants who had more than one child with an ASD diagnosis were

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[3] Participants of this study are parents of children with ASD; "participants" and "parents" will be used interchangeably throughout the results and discussion section.

asked to think about only one of their children between 6 and 17 years old for the duration of the study. This information is described in the next section.

Table 1.
Demographic characteristics of parents

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%	
	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 Children

Along with demographic information for the parents who participated in this study, 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 of the children were diagnosed with ASD with an average age of diagnosis of 5.32 years old (range: 2–13). Participants shared the functional independence of their child from three options: requiring support, requiring substantial support, and requiring very substantial support. There were 15 participants who said their child required support, 6 who said their child required substantial support, 3 who said their child required very substantial support, and 10 participants who did not discuss a concrete category. These 10 participants expanded on their response in the connected open-ended question, discussing the variation in their child's support requirements, thus choosing not to label functionality; participants mentioned how support can depend 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 learning disabilities.

Table 2.
Demographic characteristics of children

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

Recruitment

As previously discussed, parents who access support services possess particular demographic characteristics—those of which include being white and well-educated (Mandell & Salzer, 2007). It was important for this study to aim to include the voices of parents who may be left out of ASD research but continue to play an irreplaceable role in their children's lives. Recruitment efforts were made to include both mothers and fathers within minority communities through various support groups and organizations; however, majority of the participants were mothers who identified as white. The implications of these results are expanded upon in the limitations section.

Following review and clearance from the University of Guelph Research Ethics Board, recruitment was carried out through online dissemination, whereby data were collected anonymously. A broad, convenience sampling method was used to attempt to connect with the defined target population through a variety of means. Virtual posters (Appendix A) outlining the key study information were posted to Twitter and Facebook groups and sent alongside recruitment emails for organizations to disseminate through email or newsletter. Recruitment emails were sent to ASD advocacy groups and organizations providing ASD services, such as Autism Ontario, Kerry's Place, Thames Valley Children's Centre, the Child and Parent Resource Institute, KidsAbility, the Children's Hospital of Eastern Ontario, and Facebook support groups. The use of services, organizations, and social media to circulate the survey resulted in snowball sampling, whereby participants shared the survey amongst each other and increased participation rates. A copy of the recruitment email script that was sent to organizations to subsequently send to parents can be found in Appendix B. The goal of disseminating the survey through various online outlets was to provide diverse perspectives and voices with the opportunity to be heard.

Once participants provided informed consent (see Appendix C), they completed the survey and had the opportunity to enter the incentive prize draw for $25, for which one winner was chosen.

Materials

This study adopted a mixed-method approach that included a researcher-created questionnaire developed in addition to scales adapted from previous ASD research. The 42 survey questions were a combination of closed- and open-ended that asked parents 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 (Appendix D). These questions helped to gauge parental knowledge of and perceived need for support resources in Ontario. Survey questions were divided into three categories: Service Use, Ontario Autism Program (OAP), and COVID-19. There were five questions pertaining to the OAP, four pertaining to COVID-19, and eight questions pertaining to parents' use of support services—four of the service use questions required follow-up responses, when applicable. The survey included demographic questions pertaining to both the parent and the child with ASD to understand the characteristics that may influence involvement in support services. There were 11 questions about specific parent variables and six questions about the child variables. Examples of questions include: demographics (e.g., "What is your current employment status?" "What has your child been diagnosed with?"), parents' involvement in and perception of the Ontario Autism Program, parents' 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 parents' perceptions of receiving and accessing support (e.g., "Do you find it easy to seek out support or ask for help?").

Along with researcher-created survey questions, this study included seven scales adapted from previous ASD research. These measures required parents to rate various aspects of their life, such as their perception of resources and needs, support from family, friends, and professionals, resilience and well-being, and impacts to daily life (e.g., financial and social impacts). The scales that were used include: the Family Support Scale (Dunst et al., 1984), the Family Needs Questionnaire (Kreutzer et al., 1988), the Perceived Support Scale (Krause, 1995; Krause & Borawski-Clark, 1995), the Unmet Resource Needs (King et al., 2013), the Impact on Family Scale (Stein & Riessman, 1980), the Brief Resilience Scale (Smith et al., 2008), and the WHO Well-Being Index (World Health Organization, 1998). These scales were used to measure parents' perception of social support from various sources and assess their unmet needs. The measures used have reported reliable internal consistency across multiple studies, ranging from 0.77–0.91, and were demonstrated as valid. The following section provides details on each scale.

Family Support Scale

The availability, type, and helpfulness of various sources of support for parents of children with special needs are measured using the Family Support Scale (FSS). The scale, originally designed by Dunst et al. (1984), has 19 items and requires participants to rate the level of perceived helpfulness on a 5-point Likert scale ranging from "not at all helpful" to "extremely helpful;" participants can also choose "not applicable." 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). The FSS organizes forms of support into three subscales: kinship support (e.g., immediate family, spouse), informal support (e.g., friends, coworkers, other parents), and formal support (e.g., professional helpers and agencies). The kinship subscale has five items, the informal subscale has nine items, and the formal scale

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has five items. No Cronbach's alpha is provided for this scale, due to a high number of participants responding "not applicable" on multiple sources of support. For this reason, descriptive statistics are provided for the FSS in the results section.

Family Needs Questionnaire

The Family Needs Questionnaire (FNQ) is used to assess family needs and how well these needs are being met. Kreutzer et al. (1988) originally developed the measure to assess adults with traumatic brain injuries and has since been adapted to include children with traumatic brain injuries (Kreutzer et al., 1994). Siklos and Kerns (2006) modelled their study around the child version of the FNQ to obtain information specific to the needs of families with children with ASD and Down Syndrome. The updated model used 23 questions from the child version of the FNQ and included 31 new questions to assess parent-centered needs. The FNQ asks participants to rate how important the six subscales—health information, emotional support, instrumental support, professional support, and community support needs—are to their life and the extent to which those same needs are being met using an ordinal scale (yes, partly, or no). An example of the questions asked include, "I need to be well-educated about my child's disorder in order to be an effective decision-maker regarding the needs of my child." A perceived importance score is obtained by summing the total number of items rated as important and a respective needs met score is obtained by summing the number of needs that were rated as being met. This approach is based on Siklos and Kerns' (2006) study, whereby the specific items most often endorsed as met and the percentage of participants who rated these needs as met were reported. The current study utilized the parent-centred needs portion of the questionnaire, resulting in parents answering 26 questions about their support needs. The FNQ was found to be highly reliable (52 items; $\alpha = .94$).

Perceived Support Scale

The Perceived Support Scale (PSS) was developed from the work of Krause (1995) and Krause and Borawski-Clark (1995). The PSS measures participants' perceptions of help received from others, their satisfaction with support, and the support they offer to others (Krause & Borawski-Clark, 1995). These scales have been used in various studies; most often, with respect to caregiving and support for older adults. This thesis utilized the received support and satisfaction with support questions to understand the family-social environment interactions; the questions on "tangible support, emotional support, and informational support provided to others" were omitted. The PSS asks participants to indicate how often the stated tangible, emotional, and informational support was offered to them from others; response options were "not at all," "once or twice," "3 to 6 times," or "more than 6 times" on questions such as, "How often has someone provided you with some transportation?" The PSS has three subscales: tangible support, emotional support, and informational support. The responses are summed to form a single score that represents support received from others (Krause & Borawski-Clark, 1995); possible scores range from 11 to 44. The PSS was found to be highly reliable in the current study (11 items; α = .94).

Unmet Resource Needs

The Unmet Resource Needs (URN) scale was developed by King et al. (2013) to measure the unmet needs of caregivers of stroke survivors, based on findings from an earlier study. Unmet needs were defined as the "desire for more assistance, support, or information to manage physical or emotional concerns" (King et al., 2013, p. 322). The URN is a 13-item scale that asks participants to indicate their agreement with statements that address effective resources for managing emotional, physical, and behavioural responses. Participants are asked to rate their

responses on a 5-point Likert scale ranging from "strongly disagree" to "strongly agree" on questions such as, "I needed a resource or service to help with caregiving but did not have it" (King et al., 2013). Responses are summed for each participant, with the possible range of scores being 12 to 60 and higher scores indicating greater unmet needs. Adaptions to the current study include changing the phrase "the patient" to "our child" in five questions and omitting one question about using the LIFE center, as it is a patient-family resource center and not applicable to this study. The URN was found to have good reliability (12 items; $\alpha = .85$).

Impact on Family Scale

The Impact on Family Scale, developed by Stein and Riessman (1980), was designed to measure the effects of a child's illness on the family system. The 24-item scale was developed out of the assumption that changes occur in the family due to the child's illness, resulting in adaptions (Stein and Riessman, 1980). Consistent with family adaptions, both positive and negative impacts are considered within the Impact on Family Scale. The scale is divided into four dimensions, which include financial, familial/social, personal, and mastery aspects, with each item being scored as "strongly agree," "agree," "disagree," or "strongly disagree." Examples of statements include, "It is hard to find a reliable person to take care of my child" and "My relatives have been understanding and helpful with my child." The items reflect economic difficulties, social and familial impacts, and will be adapted in the current study to assess parents' perceived impact of their child's ASD. The current study adapted the measure by changing the phrase "my child's illness" to "my child's ASD" and used 17 out of the 24 questions, omitting six questions that frame the child as a negative stressor or burden to family life, such as "I think about not having more children because of the illness." The IFS was found to have acceptable reliability (17 items; $\alpha = .76$).

The Brief Resilience Scale

The Brief Resilience Scale (BRS) was created by Smith et al. (2008) to assess the ability to bounce back from adverse situations and the resources that generally provide positive adaption. The BRS is a 6-item scale, whereby questions 1, 3, and 5 are positively worded and 2, 4, and 6 are negatively worded—questions 2, 4, and 6 are also reverse coded (Smith et al., 2008). Participants are asked to rate their agreement with the six statements on a 5-point scale ranging from "strongly disagree" to "strongly agree." Examples of questions include, "I tend to bounce back quickly after hard times." The BRS was originally tested on four samples; two of which were undergraduate students and two of which were chronic pain patients (Smith et al., 2008). The current study used the scale to assess resilience in parents of children with ASD and the correlation to support resources. The BRS was found to have good reliability (6 items; $\alpha = .87$).

WHO-5 Well-Being Index

The Well-Being Index, created by the World Health Organization (1998), is used to measure participants' well-being during the two-week period prior to taking the survey. It is a 5-item measure that requires participants to rate statements such as, "I have felt calm and relaxed," on a 5-point scale ranging from "all of the time" to "at no time," with "all of the time" representing a five and "at no time" representing a zero (World Health Organization, 1998). The score is calculated by totaling the figures for each answer—a score of zero represents worst possible mental health and 25 represents the best possible quality of life (World Health Organization, 1998). Participants who answer 0 to 1 to any of the five items or score below 13 may indicate poor well-being. The WHO Well-Being Index was found to be highly reliable (5 items; $\alpha = .93$).

Design and Approach

A mixed methods approach was utilized for this study, which is an approach to inquiry that involves "collecting both quantitative and qualitative data and integrating the two forms of data" (Creswell & Creswell, 2018, pg. 52). Integrating quantitative and qualitative data is done through merging the data, explaining the data, or embedding it within a larger framework (Creswell & Creswell, 2018). Mixed methodology provides a complex approach to the research that allows for a more complete understanding of the research questions and compares different perspectives drawn from the data. The current study utilized a convergent mixed methods design—a single-phase approach, whereby quantitative and qualitative data were collected, analyzed separately, and then compared to determine any convergence or differences (Creswell & Creswell, 2018).

The quantitative portion of the data aided in understanding the specific population demographics, measured the proportion of participants who use support resources, and measured participants' perception of support needs through scales. The qualitative data were used to examine the various factors that influence parental perceptions of support needs (e.g., involvement in the OAP, impacts of COVID-19). Descriptive statistics were used to answer the demographic questions and correlations were run using participants' total scores from each scale measures to identify any basic correlations between the scales and subscales.

The qualitative questionnaire items were analyzed using thematic analysis. While the quantitative data analysis helped to understand the participant characteristics and service use characteristics, the qualitative analysis brought deeper insight into the experiences of participants and how they view support.

It is important to note that data collection occurred during COVID-19 from September to December 2020, whereby province-wide restrictions were in place across Ontario. During the time that the survey was open, the province introduced a five-tiered, colour-coded system that regulated different measures for each public health unit. While data were not collected on participants' specific geographical location, it can be assumed that most participants were experiencing varying levels of restrictions. These restrictions included social distancing measures, limitations on school participation, and complete lockdowns in some parts of the province. With this in mind, it is likely that participants each experienced these pandemic-related restrictions in different ways.

Data Analysis

The data collected in the survey were analyzed using Spearman's rank-order correlation and thematic analysis. In addition, a descriptive statistical analysis was conducted to obtain demographic information for the participants and their children. The statistical analyses were conducted using IBM's Statistical Package for the Social Sciences 27 (SPSS) and the qualitative analysis was conducted using NVivo 12.

The descriptive analysis provided sample sizes, means, standard deviations, and percentages for the demographic questions included in the survey for parents and children. Results from the descriptive analysis provided an overall summary of the sample population included in this study and insight into the variables influencing parents of children with ASD to seek support.

For the quantitative data collected through scale measures, Spearman's correlation tests were used to measure the relationship between variables. The Spearman's correlation coefficient (r_s) was used to identify the strength and direction of association between two variables

measured on an ordinal Likert scale. To begin, correlations were run on all the subscales to identify any initial correlations across all subscale rankings. The results were then presented in SPSS in a matrix that depicts Spearman's correlation, its significance value, and the sample size that the calculation was based on. Results from the correlation tests were used to assist in answering research question 1.

For the qualitative data collected from the open-ended questions, thematic analysis was used to identify the dominant themes provided by the participants in response to questions about service use, the OAP, and COVID-19. 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 is 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.

The current study followed the six phases of analyses, as outlined by Braun and Clarke (2006), to provide a framework for coding the qualitative data. Thematic analysis, as illustrated by Braun and Clarke (2006), is a method for systematically "identifying, [analyzing], and reporting patterns [of meaning] within data" (p. 79); however, it frequently goes beyond these basics to interpret various aspects of the research. Thematic analysis is a foundational method for qualitative analysis, whereby the approach is diverse, complex, and nuanced (Braun & Clarke, 2006). Braun and Clarke (2006) discuss six steps to analyzing data: data familiarization, generating initial codes, searching for themes, reviewing themes, defining and naming themes, and producing a final report. It is important to note that thematic analysis is not a linear process, but rather a recursive process that moves back and forth throughout the phases, as needed (Braun

& Clarke, 2006). The qualitative responses were analyzed using NVivo and the results were used to answer all three research questions.

Following the collection, identification, and analyzing of both sets of data, the main findings from quantitative scale scores were compared and integrated with the perspectives of parents. The integration of results consisted of merging the results in a side-by-side comparison to yield convergences, divergences, and differences between concepts, themes, and scales (Creswell & Creswell, 2018). The quantitative data were analyzed first to understand the sociodemographic characteristics of the participants. The demographic information was necessary to determine whether the participants were representative of and generalizable to the target population. The scale results gave a general overview of participants' perceptions of support resources. Following the analysis of the quantitative data, the qualitative data were analyzed to understand participant experiences with caregiving, the service system, and COVID-19. The process of analyzing the quantitative and qualitative data was not a linear process; instead, the process involved moving back and forth between the scale results and the open-ended responses to compare the data. This mixed methods approach involved triangulation based on integrating the data and developing comprehensive conclusions.

Analytic Strategy

Table 3 outlines the research alignment table that guided the current study, which includes the proposed research questions, the specific data collected for each question, and the corresponding analytical methods.

Table 3.

Research Alignment Table

Research questions	Specific data being collected i.e., measures	Analysis method
Descriptive information of parents	• What is your age? • Which gender identity do you identify with? • What is your race/ethnicity? • What is your marital status? • What is the highest degree or level of education you have completed? • What is your current employment status? • What is your estimated yearly household income? • Do you live in an urban area or in a rural community? • How many children do you have? • Has one or more of your children been diagnosed with ASD? • How many children have been diagnosed with ASD?	• Descriptive analyses for sample size (N), means, standard deviations (SD)
Descriptive information of child with Autism Spectrum Disorder	• What is your child's age? • What is their gender? • What has your child been diagnosed with? • What was their age at diagnosis? • What is your child's level of functional independence (e.g., requiring support, requiring substantial support, or requiring very substantial support)? • Does your child have any comorbid conditions (e.g., one or more conditions occurring alongside your child's ASD, such as ADHD?)	• Descriptive analyses for sample size (N), means, standard deviations (SD)
To what extent do parents perceive support resources to be effective in supporting their needs? To what extent are they perceived as available and accessible?	• Please describe the interventions or treatments that your child currently receives. • What changes have there been to your life since your child was diagnosed? • Do you feel that you receive the supports you require to best support your child? Please explain. • Do you find it easy to seek out support or ask for help? If not, why? • Is there anything preventing you from getting support? If yes, what? • Are there any supports that you require by have been unable to access? If yes, please describe. • What are your expectations when seeking support? • What type of support/who do you rely on the most when faced with difficult or adverse situations? • Family Support Scale • Family Needs Questionnaire • Perceived Support Scale • Unmet Resource Needs Scale • Impact on Family Scale • The Brief Resilience Scale • WHO-5 Well-Being Index	• Thematic analysis • Mean and total scores; Spearman's correlations

Research questions	Specific data being collected i.e., measures	Analysis method
How have the recent changes to the Ontario Autism Program impacted parents' perception of available and accessible supports?	• Are you currently using the Ontario Autism Program? (if not, explain why) • If applicable, how much funding does your child receive from the OAP? • How has the program impacted your life? (e.g., ability to find treatment for child, ability for time alone, time to do things for yourself, etc.) • Please describe any concerns you have with the program (if any). • What could the OAP do to better meet your needs and your family's needs?	• % counts, thematic analysis • Thematic analysis
What role has COVID-19 played in the availability and effectiveness of service delivery?	• What aspects of your life have changed since COVID-19 began? (e.g., limited services, homeschooling) • What changes occurred to your support services due to COVID-19 (e.g., loss or cancellation of services, change to remote delivery)? Please explain • Please explain the ways that this time has affected your well-being or mental health • What have you been doing to cope with life during COVID-19?	• Thematic analysis

Data Cleaning Process

The Qualtrics survey was published on September 24, 2020 and closed on December 21, 2020 with a total of 67 responses. A master copy of the data set collected through Qualtrics was downloaded to Microsoft Excel. Data cleaning began with assigning each participant a participant ID using randomized numbers of 1 through 67 in Excel. Following this, the data cleaning continued with the exclusion of participants based on three criteria (Figure 1). First, participants who completed less than 90% of the survey were removed ($n = 30$). Next, participants who did not identify as having a child with ASD were excluded ($n = 1$). Finally, participants who made it to the end of the survey but did not answer any questions were excluded ($n = 1$). One of the requirements to participate in this study was to have a child between the ages of 6 and 17; however, there were four participants who were included in the study who had children under the age of 6. By including these participants, it is possible that these children may receive more funding and thus, an increase in available and accessible support. After the

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exclusions, the final sample consisted of 35 participants. Using these data, a copy was exported to SPSS to conduct the quantitative analyses and a copy was exported to NVivo to conduct the qualitative analyses.
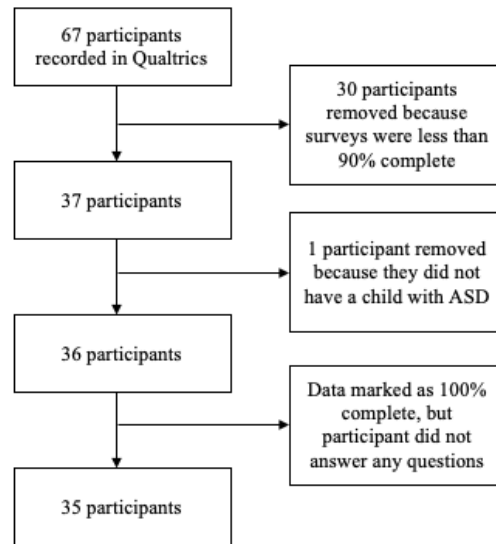

Figure 1. *Flow chart of participant sample based on exclusion and inclusion criteria.*

Results

The results of this study are organized by research question. The experiences of parents of children with ASD are not compared with parents of neurotypical children in the current research. Previous research has explored the differences between the two populations, but this study aimed to solely focus on the perception of support needs for parents of children with ASD to understand where gaps in services and resources are present.

The Perceived Availability, Accessibility, and Effectiveness of Support Resources

The first research question in this study aimed to assess the extent that parents perceive support resources to be effective, accessible, and available in supporting their needs—this support includes instrumental, informational, and emotional support from kinship, informal, and

formal resources. The results from this section include participants' open-ended responses, as well as descriptive statistics for the scale measures which are presented below.

Table 4.
Descriptive statistics for scale measures

Variable	*n*	Mean Score	SD	α
Family Support Scale (FSS)	35	52.97	9.98	N/A
Family Needs Questionnaire (FNQ)[a]	35			0.94
Perceived Support Scale (PSS)	35	23.00	9.41	0.94
Unmet Resource Needs (URN)	35	35.37	8.28	0.85
Impact on Family Scale (IFS)	35	50.42	6.84	0.76
Brief Resilience Scale (BRS)	35	3.28	0.81	0.87
WHO Well-Being Index	35	10.00	5.96	0.93

[a] Mean score and standard deviation were not calculated for the FNQ. The results were calculated by totalling the number of needs participants rated as important and unmet and compiling a list.

Participants were first asked to describe the interventions or treatments that their child currently receives and any changes to their life since their child was diagnosed to understand what participants are experiencing in their family lives. Parents reported similar interventions and treatments, including behavioural services (e.g., Applied Behavioural Analysis [ABA], Intensive Behavioural Intervention [IBI]), therapies and other specialized services (e.g., Speech Language Pathology [SLP], Occupational Therapy [OT], Physical Therapy [PT], and counselling), medication, school-based services, social and life skills, and technology-based devices. Additionally, multiple parents indicated that their child is currently not receiving any services due to being on the OAP waitlist or seeking out options now that they have a diagnosis. In terms of changes to family life since their child's diagnosis, the following themes were found in parent responses: financial stress, grieving for their child's future, changes to schooling, accommodating routines and adjusting environments, social changes, having a better understanding of ASD, and engaging in advocacy. This is not an exhaustive list of experiences because, as participant #36 stated, "our lives are changing daily." Parents responded to the IFS, which was adapted for this study to measure the perceived impact of receiving an ASD diagnosis

on family life. The range of scores for participants was 38 to 68, with a mean score of 50.42 (SD = 6.84).

Participants were also asked to identify service use characteristics and their experiences with support resources. When asked if parents receive the support required to best support their child, most parents responded negatively or explained where supports were lacking. These parents outlined accessibility barriers, financial constraints, limited community-based supports, and programs that are not centred around the individualized needs of children. When asked about the type of support that parents typically rely on, participants identified support types that fit into four different support categories: 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 EAs. Participant #34 found formal support to be particularly important:

His psychotherapist has been with us since he was young. She is wonderful. My husband and I email with her and have a monthly chat with her. My son sees her (currently on Zoom) weekly.

Participant #40 also cited the importance of professional helpers: "We have family support worker through Community Living who is very available and amazing at helping navigate everything. She even will come to appointments and ask all the right questions." Parents discussed that they have previously relied on 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."

While there were distinct types of support that parents relied on (e.g., family support worker, local social media groups, other parents), almost all participants indicated that they rely on multiple combinations of support for their family, depending on the situation. Parents who responded that they rely on themselves or their partner for support explained that it is because of their knowledge and understanding of how to best support their children. Participant #21 said: "I will do the research and do what I need and can do for my daughter by myself with little help from others." Similarly, participant #5 said that they rely on themselves and their connection with their partner because other forms of support are "inconsistently able to meet the needs of [their] dual exceptionality (ASD and gifted) teen." Parents also reported that they did not know who else to ask nor did they want to overburden others with requests for help. Participant #52 said:

> I don't know who to call … I try to manage with what I can and find my own way first. I think it stems from not wanting to burden others or to worry anyone. I think it's mostly because I don't want to worry my family.

When asked if it is easy to seek out support, the majority of parents responded negatively, explaining that this was due to both internal and external factors. Some parents find it hard to seek out support because of their stubbornness, not wanting to overburden others, or not knowing where to look. Other parents find it difficult due to COVID-19 restrictions, waitlists, financial constraints, and a service system that offers restrictive support. It is important to note that those who responded positively explained that they frequently advocate for themselves or their children and know the language required to ask for help. Participant #63 encapsulated this by saying 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. Additionally, some parents said it can be easy to seek out formal support, but they never actually receive support.

When parents were asked if anything was preventing them from getting support, 85.7% responded with yes or explained what has prevented them from seeking support. Parents cited multiple reasons, such as financial and location constraints, little support from the government (e.g., long waitlists to programs, limited funding), a lack of accessible services, and distrust in service providers. In particular, distrust resulted from professionals who do not understand the varying presentations of ASD. Participant #14 said: "teachers and EA's [are] not always educated [about] autistic learners. Last year the teacher caused significant damage to [my] child because she did not understand autism and refused to learn about my child." Furthermore, one parent said that they were skeptical of trusting others because her child is "partially verbal and will not tell me when he has had a bad day or being mistreated" (#52). There were a small number of parents who felt left out of the process, whether that was through school-based services or government processes. One parent felt they were "dismissed a lot of the time" (#40), while another felt "left out of the process [of] creating an interim IEP to support my child" (#63). When asked if there were any supports families required but could not access, parents provided supports for both themselves and their children. These supports included EA/school supports, social groups for children, SLP/OT, ABA, and support groups for parents. Finally, parents were asked what their expectations were when seeking support. Many parents indicated their expectations relative to seeking support from professionals: accessible, available, compassionate, timely, tailored to their child's individual needs, and understanding ASD beyond stereotypes and the typical presentation of symptoms. Participant #48 described current services as being delivered through a framework of "stereotypes, ableism…[and] how visible a disability is," and they wanted service providers to

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better understand the heterogeneous nature of ASD. Ableism in ASD services is comprised of "beliefs and practices that devalue and discriminate against people with disabilities and often rests on the assumption that these people need to be fixed" (Bottema-Beutel et al., 2021, p. 19). Parents also wanted to be included in the decision-making process; participant #62 highlighted this by saying: "I want to learn [about] my son's diagnosis, so I can help the best way I can at home. I want to learn more so I can have a better understanding." Some parents outlined their expectations when seeking support for themselves, such as someone who validates their concerns, offers tangible support, and understands their family's needs. A few parents noted that they do not know what to expect or try not to have expectations to avoid disappointment: "I have [no expectations]. Never expect anything from anyone and you will never be disappointed" (#30).

To measure participants' perceptions of available supports, participants were asked to indicate the perceived helpfulness of kinship support, informal support, and formal support. Participants' perceptions were measured using the 19-item Family Support Scale (FSS), which asks participants to rate the level of perceived helpfulness of each source listed, including family members, spouse or partner's family, friends, community members, and professional agencies. Total scores are calculated for each participant by adding together all responses, whereby the range of scores for participants was 39 to 78, with a mean score of 52.97 (SD = 9.97). Due to multiple questions where many participants rated the source of support as not applicable, the variables within the FSS will be reported on as categorical and descriptive statistics will be provided due to missing data. The sources rated as not applicable include church members/ministers, co-workers, and early childhood intervention programs. Almost all of 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 daycare centres, and

the family's or child's physician. The descriptive statistics for the FSS can be found in Table 5.

Table 5.
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/daycare center	*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.

Participants were also asked to indicate the perceived availability of tangible, emotional,

and informational support using the 11-item Perceived Support Scale (PSS). The range of scores

for participants was 11 to 44, with a mean score of 23 (SD = 9.41). To measure participants'

perceptions of the effectiveness and availability of supports, participants completed the 12-item

Unmet Resource Needs (URN) scale and the 26-item Family Needs Questionnaire (FNQ). The

range of URN scores for participants in this study was 18 to 60 with a mean score of 35.37 (SD =

8.28), with 60% of participants recording a score of 36 or less. Participants rated the FNQ

questions in terms of how important they were to their lives and how well these needs were

being met. As there is no total or mean score calculated for this scale, the top 10 needs that

participants rated as "important" or "very important" can be found in Table 6 and the support

needs most frequently rated as "partly" or "unmet" can be found in Table 7.

Table 6.

Top ten needs most frequently rated as "important" or "very important"

Item endorsed	%
I need to have my questions answered honestly	100%
I need to be well-educated about my child's disorder in order to be an effective decision-maker regarding the needs of my child	97%
I need to be shown that my opinions are used in planning my child's treatment, therapies, or education	94%
I need to have a professional to turn to for advice or services when my child needs help	94%
I need to be shown respect by the professionals working with my child	94%
I need to have information regarding my child's therapeutic or educational progress	91%
I need to be actively involved in my child's treatments and therapies	89%
I need to get enough rest or sleep	86%
I need to have the professionals working with my child to speak to me in terms I can understand	83%
I need to have time to spend alone with my partner	74%

Table 7.

Important needs most frequently rated as "partly met" or "unmet"

Item endorsed as unmet	%
I need to be told if I am making good decisions about my child	80%
I need to spend time with my friends	74%
I need help in remaining hopeful about my child's future	74%
I need to be shown respect by the professionals working with my child	<u>74%</u>
I need to have my questions answered honestly	<u>71%</u>
I need to have help in deciding how much to let my child do by him/herself	71%
I need to get enough rest or sleep	<u>71%</u>
I need to be told why my child acts in ways that are different, difficult, or unusual	69%
I need to have counseling for myself and my spouse/partner	69%
I need to discuss feelings about my child with a parent who has a child with the same disorder	66%

Note. Underlined percentages indicate the item is also one of the ten most important needs.

Finally, parents responded to questions about their resilience and mental health over the

two weeks before filling out the survey. These were measured using the 6-item Brief Resilience

Scale (Smith et al., 2008) and the 5-item WHO Well-Being Index (World Health Organization, 1998). Mean scores for each participant were collected for the BRS; scores ranged from 2 to 5, with a mean score of 3.28 (SD = 0.81). Total scores were collected for each participant for the WHO Well-Being Index, ranging from 0 to 25; the mean score was 10 (SD = 5.96).

Following the calculation of total or mean scores, Spearman's correlation tests were run across 10 support and family adaption subscales. The results suggest that 14 out of 45 correlations were statistically significant (see Table 8). The correlations of the FSS kinship support with other subscales were not significant, except for the IFS social impacts subscale, $r(35) = -.52$, $p < .05$. Some interesting findings will be expanded upon in the discussion section, such as the relationship between the FSS informal subscale and the PSS informational support subscale and the FSS informal support and the PSS emotional support subscales.

Table 8.
Spearman correlation matrix among 10 subscales

Variable	n	M	SD	1	2	3	4	5	6	7	8	9	10
1. FSS Kinship Support	15	13.00	4.90	—									
2. FSS Informal Support	7	15.29	4.23	.87	—								
3. FSS Formal Support	14	14.00	5.53	-.11	1.00**	—							
4. PSS Tangible Support	35	9.54	4.17	.45	.72	.54*	—						
5. PSS Emotional Support	35	7.40	3.14	.45	.85*	.66*	.72**	—					
6. PSS Informational Support	35	6.06	2.93	.27	.87*	.59*	.66**	.72**	—				
7. IFS Financial Impacts	34	9.94	1.79	-.41	-1.55	-.35	-.03	-.23	-.41*	—			
8. IFS Social Impacts	35	14.00	3.60	-.52*	-.13	.01	-.45**	-.21	-.27	.25	—		
9. IFS Personal Strain	35	14.89	3.17	-.15	.28	.01	-.21	-.09	-.33	.43*	.63**	—	
10. IFS Mastery	34	11.71	2.54	.49	.47	.44	.23	.20	.27	-.27	-.18	-.28	—

*$p < .05$. **$p < .01$.

Effect of the Ontario Autism Program on Parents' Perceptions of Support

The second research question aimed to understand how the current Ontario Autism Program (OAP)—and the recent changes to the program's format—have impacted parental perceptions of available and accessible supports. These changes included providing interim early years supports for children on the waitlist and renewing one-time funding during COVID—in addition to the core clinical services mentioned earlier (Government of Ontario, 2020). Participants were asked if they are currently using the OAP, how much funding they receive, how the program has impacted their life, any concerns with the program, and what the OAP could do to better meet their family's needs. In terms of program involvement, 63.6% of parents indicated that they were currently using the OAP. The remaining parents who indicated that they were not using the OAP shared reasons such as they had been waitlisted, they had lost track of applying, and they did not know about the program. If applicable, parents were asked to specify how much funding they currently receive from the OAP. The amount of funding from the OAP was diverse across participants; some participants received $20,000, some received $5,000, some did not receive any, and some did not concretely specify (e.g., "a lot," "enough to cover 21 hours/week," "much less than we need"). It is important to note that most of the parents who responded that they are not using the OAP are currently on the waitlist.

Four themes were found in responses from participants who indicated that they used the OAP: barriers to service access, restrictions on funding, appreciation for support, and uncertainty about the future. Each of these themes will be discussed in the following sections.

Barriers to Service Access

When considering how the OAP has impacted their lives, parents identified barriers to accessing services that included perceiving the system as difficult to navigate, experiencing a

lack of guidance from professionals, issues with waitlists, and a confusing application process. Participant #4 discussed how these issues had been present since their child's diagnosis: "I feel like after the diagnosis, I was given a giant pile of information and told to sort it out and figure out a treatment plan by myself… [I need] more clarity in what is offered." Parents found that information about the program was confusing and contradicting, but there was no one to talk to about funding and eligible expenses. Without guidance, parents said that they cannot find therapies. One parent, who grew up using technology with ease, said that the application process is difficult to navigate. Additionally, parents reported that travel distances and costs can be prohibitive and the system itself is confusing, especially for families for whom English is another language or are marginalized in some other way. Some parents recognized that, while they have received some level of support from the OAP, numerous families do not receive the same services, such as Francophone, Indigenous, and low-income families.

Parents also described the OAP's lengthy waitlist as atrocious—many families had to wait years for funding, and some were pushed out of the program due to cutbacks and changes. Parents were cognizant of how the waiting time intervenes with the critical period for early childhood interventions. One parent said that, "waiting 3 years for $20,000 is not help" (#22), indicating the limits to the OAP's funding eligibility. These barriers have increased stress, anxiety, and worry for parents. Parents discussed the time that is spent focusing on finding support for their child has made them feel incredibly stressed and overwhelmed.

Restrictions on Funding

Parents who discussed funding were concerned with the restrictions on how funding can be spent and how little money the program offers. Many parents were only able to purchase one form of therapy (e.g., ABA) because the funding they received did not cover anything else.

These restrictions were due to the program not providing enough age-based funding and facing

limitations on where funding can be spent. For some parents, the money they received did not

even cover therapy costs for a quarter of a year. Other parents were forced to choose which

services were more important:

> It is not enough for ABA therapy, which my son needs, nor is it enough for respite. I
>
> looked at all the things he needs, and decided based on his needs and the cost, that we
>
> could get the most out of OT and SLP and parent training with the $5000 (#63).

Many parents knew which supports and services their child needed, but they could not afford the

costs even with the OAP aid. This was seen by participant #63 who said that "$5,000 is not

enough… [it] won't even cover a year of ABA for my son." Furthermore, parents discussed the

need for adequate funding alongside the freedom to choose their service providers:

> Allow us parents to be able to purchase things we need for our child(ren) with the
>
> funding many waited so long for without restrictions. To be able to use the funding how
>
> we see fit and what is best for our child's needs, especially during lockdown (#18).

Parents indicated that the OAP offered a restrictive list of services and "only covers ABA…

ABA is not all that children on the spectrum need" (#55). Participant #57 echoed this and said

that: "current funding is only for one type of therapy [ABA], but ASD affects multiple domains

and ABA doesn't address them all." Due to the limited funding that parents received, many

reported that they previously paid for services out-of-pocket and continue to do so for what their

funding does not cover. Some parents found that the OAP has helped and continues to help them

access specialized services, but many are feeling the burden of out-of-pocket expenses. Due to

COVID-19, children were unable to access the services they would normally receive and

restrictions on travel meant that parents had to seek services elsewhere. This caused additional

strain for families who have a limited time to use their funding, as it does not roll over into the next year. As participant #35 said, "[I only have] one year to spend it… what if the intervention we need isn't available due to COVID?" Parents wanted to program to be flexible in what can be covered under the OAP, especially during COVID-19 where their needs have been altered.

Appreciation for Support

A few parents provided responses that showed their gratitude towards the OAP and offered insight into how beneficial it has been for their family. Participant #19 said that, "without it, we would be unsure of where to turn to and would not have made the necessary connections nor would our child have made the progress that he has." Two themes were identified in parental responses discussing their gratitude: the program offsetting costs for services and the program providing the appropriate treatment for their child. One parent explained how they have been able to purchase "high priced items to help, such as an indoor swing, a tablet sound machine, and a light projector" (#52), while another said the program has relieved some financial burden. Additionally, the program has provided weekly therapies for children, helped with tutoring, and helped children learn new social and communication skills. Parents reported being satisfied with the support they were receiving and said that the program gave them hope.

Uncertainty about the Future

When discussing their views of the OAP, many parents' responses outlined worry over the future of the OAP and what their involvement in the program looks like. The most prominent concern parents had was that the current OAP is not a needs-based program. Almost all the parents who provided recommendations for the future OAP discussed the need to eliminate age- and income-based eligibility and move towards an inclusive, needs-based program. These discussions included moving away from funding only one type of therapy (e.g., ABA) to invest

in inclusive education, accessible health care, and accessible employment or job programs. One parent, who advocates against the use of ABA, offered some direction for the new OAP:

> Consult with autistic adults, who I have learned the most from, about school access, health care access and accessible employment. Value their perspectives and hire them to develop and manage programs. Autism services are based on an old model that doesn't work for people today. Get rid of the old guard and bring in new ideas (#34).

Parents offered similar responses, such as participant #52, who indicated that the OAP should "take into consideration other forms of therapy and not just provide a one-size-fits-all model of support." Additionally, parents were doubtful of the government's promise to introduce a new autism program, based on their previous experiences:

> The announcement of "foundational family services" was extremely insulting. I was already accessing those supports for free through Kerry's Place and Autism Ontario. There was nothing new made available to me with "foundational family services," but it made a great headline for the government. Families not directly dealing with ASD would see the announcement and think "good job they're offering services," but there was nothing new being offered" (#63).

Ultimately, parents were concerned that "nothing will be put in place next year" (#52). Many parents shared similar fears because they did not know when the new program would be rolled out and the future of their support was unknown.

Effect of COVID-19 on the Availability and Effectiveness of Service Delivery

The third research question aimed to understand how COVID-19 has impacted the availability and effectiveness of service delivery. Participants were asked what aspects of their lives have changed since COVID-19 began, what changes have occurred to their support

services, the ways that this time has affected well-being and mental health, and how they are

coping during this time. Participants' responses were created into four themes: adapting to

alternative service delivery, disruptions to typical routine and structure, building family

relationships, and taking care of self. Some parents did not fit into these themes and offered

responses that more broadly emphasized how COVID-19 has impacted their lives. These parents

had either responded that "everything" had changed since the pandemic began, offering no

additional details, or that "nothing" had changed because downtime was previously built into

their family life.

Adapting to Alternative Service Delivery

Parents who currently receive services for their children discussed the changes to service

delivery during COVID-19, which included the switch to remote and 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. Speech

language therapy, occupational therapy, behavioural therapies, social activities, and schooling

were all moved to remote delivery at the time of this survey due to restrictions put in place by the

Ontario government. Most of the parents who discussed the move to remote delivery reported

that the limited opportunities for service access have provided 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 echoed by other parents, whose children are

receiving limited time with their regular professional service providers. Even with the limited

services available, 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. Additionally, some parents were worried about the pandemic-related restrictions on access to health care. Children were missing regular visits with their general practitioners and, as one parent stressed, "there could be health issues that [my son] is not mentioning because of his lack of body awareness" (#34). At the time of the survey, parents reported that they were only in contact with medical professionals virtually, which increased concern for parents whose children are unable to express how they are feeling.

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 the school-related 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).

Disruptions to Typical Routine and Structure

Alongside adjusting to virtual and remote 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 lost recreational activities, social skills classes, and activities that assist with sensory needs, such as swimming. For one parent, their son "can't ride the bus whenever he wants, he can't go to the park… and he doesn't understand why" (#67). As a result of the cancellation of social activities, parents were worried about seeing a regression in their child's

social and developmental progress. For example, parents indicated that, without a regular schedule that includes programs and services, 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]."

Parents discussed how their children are experiencing an increase in stress, anxiety, and behavioural outbursts due to the change in routine. Their children were anxious due to not understanding COVID protocols or why others are wearing masks, and some were fearful of potentially contracting the coronavirus. A small number of parents reported that they noticed an increase in behavioural outbursts because their child was frustrated with the lack of social interactions outside of the home. These outbursts have resulted in more child-to-parent violence and violence between siblings that have increased stress for parents.

The loss of daily routines also resulted in changes to the family structure for most families. Participant #63 said:

> Being home around the clock together was a shock. My son always had school, my partner and I always had work, there was organically a regular schedule that involved us being apart for part of the day. And suddenly being all together 24-hours-a-day was a shock.

Some parents were adapting to working from home while caring for their child(ren), while others had been laid off or quit work to care for their child permanently. Parents struggled with feelings

of isolation and burnout from adapting to the changes of supporting their children at home and engaging them without leaving the house. Some parents felt that it was harder to meet the needs of their child, due to less support and fewer opportunities for socialization. Parents were overwhelmed from having little to no 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). Additionally, participant #51 identified more strain due to limited opportunities to "see [their] friends, which had an important, therapeutic effect for everyone." Some parents reported that this was the lowest their mental health had ever been—they felt little motivation or energy to do things that were important to them and daunting tasks could feel very overwhelming.

A small number of parents identified that they were less stressed with the adjustments and changes to their normal routine. Staying at home and limiting social interactions caused less stress for participant #30, who said that they did not have to worry about family always trying to visit or friends wanting to travel. These parents found it easier to get through the days and were experiencing less worry,

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.

Building Family Relationships

As a result of spending more time at home, parents discussed how they were working to become stronger as a family. Participant #36 said that, "we see less of our family and friends, but at the same time we have become closer as a family." Parents were spending more time trying new activities together as a family, giving each other breaks when needed, and communicating when someone is stressed or having a bad day. For example, many parents said that they had spent more time outside than at home—going for bike rides, camping, or walking. Parents also mentioned how the pandemic has kept their family grounded and connected: "it suits us to stay close to home. Shrinking our world has benefitted my child" (#64). Some parents even mentioned how they were happiest at home with their children where they can focus on supporting each other. Participant #34 shared that:

> 9 out of 10 days are good and we keep to a schedule. On that 10th day, I take a rest. We let go of expectations and do things the easy way… Sometimes my son has a bad day too and we do the same—make it an easy day.

Many parents acknowledged that they have grown closer as a family and that they continue to persevere through the pandemic.

Taking Care of Self

When responding to the COVID-19 questions, many parents offered insight into how they were coping and taking care of themselves during the pandemic. Some parents had taken up counselling, psychotherapy, and medication to mediate mental health impacts, while others took the time to do things for themselves. 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 found

themselves focusing on their child as a way to cope and ignore everything else; however, this

coping mechanism was described as "very unsustainable" if it were to continue (#63).

On a broader level, parents said that they were trying to take everything one day at a time

and take breaks when needed. These responses included one parent who set boundaries between

work and family life by "[setting] some limits on work to help and not booking meetings over

the lunch hour" (#5). A small number of parents reported that taking care of themselves meant

recreationally drinking and smoking marijuana to relax when their children were asleep.

Discussion

The primary purpose of this thesis was to examine the role of formal and informal

support resources in the lives of parents of children with ASD. This study followed a mixed-

methods research design whereby 35 participants completed an anonymous, online survey. The

survey included both closed- and open-ended questions, in addition to standardized scales

adapted from previous literature. 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 three overall objectives: to examine parents' perception of

available, accessible, and effective resources; to examine how the Ontario Autism Program has

impacted support; and to understand the role that COVID-19 has played in service delivery. The

following section will also discuss the strengths, limitations, and recommendations for future research.

The current study asked parents to indicate the age that their child was diagnosed and the different interventions and treatments their child currently receives. More than half of participating parents (67.7%) reported that their child was diagnosed before the age of 4. The importance of early diagnosis is seen in previous literature, where early identification and interventions are critical for children with ASD, as quality treatment can improve social-communicative, cognitive, and behavioural outcomes over time (Irvin et al., 2014; McIntyre & Zemantic, 2017; Stahmer et al., 2019; Volden et al., 2015). In addition to positive childhood outcomes, early diagnosis can provide parents with the tools and knowledge to support their family and decrease barriers to early intervention funding (Koegel et al., 2014). Parents in the current study highlighted the importance of early intervention for their children, recognizing that publicly funded programs should be a top priority for promoting healthy child development. Some parents cited this as one of the barriers to receiving treatment for their child, as well. Children who had previously been on the OAP waitlist for an extended period or who are still waiting for funding missed out on a timely assessment, planning, and treatment process. Several parents reported that they had been on the waitlist for up to four years and they had lost hope in receiving timely services from the government. These parents had a diagnosis but could not do anything about it due to being on the waitlist and thus, are missing out on the critical period for early interventions. Volden et al. (2015) found that the variation in service delivery for children with ASD represents an increased demand for and decreased availability of service provision. This finding was confirmed in the current study, whereby the demand for formal services in

Ontario continues to increase, while perceptions of available and accessible services continue to decrease.

Parents who provided insight into their child's interventions and treatments reported that their child used multiple services; the most common service being speech-language pathology (SLP). This finding confirms previous research, whereby Green et al. (2006) found that children utilized speech therapy the most. It is not surprising that this is the most commonly used treatment, as differences in clinical levels of social communication are a defining feature identified by the DSM-5. This finding could also be explained by parents who assume that mainstream interventions, such as SLP, are based on evidence and are readily available (Grant et al., 2015). The second most cited treatments were occupational therapy (OT) and Applied Behaviour Analysis (ABA). Similar to SLP, occupational therapy is assumed by parents to be a trusted mainstream intervention, thus contributing to an increase in use (Grant et al., 2015). The use of behavioural interventions, such as ABA, has increased over recent years due to the implementation of treatments aimed at teaching new behaviours (Green et al., 2006). An increase in using behavioural treatments may be due to reports of positive outcomes; however, a few parents in this study rejected the use of ABA and viewed these techniques as harmful. These parents viewed the government-regulated services as restrictive and based upon a deficit model of disability. Some parents said their child used ABA but recognized that behavioural therapy does not address the multiple domains that ASD affects nor does the OAP provide enough funding to cover the costs of year-round therapy.

Nearly all children diagnosed with ASD receive some form of intervention, depending on dosage, type, and setting (Irvin et al., 2014; Volden et al., 2015), which was seen in the current study. Mackintosh et al. (2005) found that children with ASD receive more than one type of

service, with many receiving up to seven different services. While parents in the current study only reported up to four different services, these findings reinforce the vast array of interventions needed to target specific developmental areas. It is important to understand this variation for families, as it highlights the differences in service utilization and largely contributes to parents' satisfaction with and perception of the service system. Another contributing factor is how an ASD diagnosis has impacted families' lives and their involvement in services. The theme of financial stress was prominent across participant responses, which included the strain of paying out-of-pocket for services and adjustments to employment as the result of inconsistent treatment schedules (e.g., becoming a stay-at-home parent, reducing hours). The IFS results in the current study indicated that financial impacts for these parents were greater than social, personal, and mastery impacts. Over 60% of parents scored a 10/12 or higher on the financial subscale. This result can be looked at in conjunction with the responses to questions about the OAP, whereby parents raised concerns about the restrictions on funding. Many families received limited funding, due to program eligibility that is dependent on the child's age and a restrictive list of services on which to spend the funding. The financial constraints, in addition to the limited support received from the government, have prevented many families in the current study from receiving the support they expected and needed.

To understand the role of support and what sources of support (e.g., instrumental, emotional, informational, financial) parents utilize, parents were asked to describe whom they rely on for support and if they receive the support required to best support their child. A majority of parents responded that they did not feel as though they received the necessary support and appeared to prioritize the needs of their child over their own. Parents who did not feel supported did not specifically comment on whether they feel supported; instead, they framed the perceived

71

level of support in terms of how supported their child was (e.g., receiving government funding or treatments). A main finding of the current study is that these parents conceptualized the idea of "we," rather than describing their perceptions of support. It can be assumed that parents are recognizing support in terms of their child and considering the impacts on the entire family. Understanding how parents talk about and frame sources of support is an important step in answering the first research question. Parents who did not identify themselves when discussing support seem to be putting aside their support needs to focus on the needs of their child. These parents valued interventions and treatments as they related to their child suggesting that the support their child receives is directly related to parents' emotional state and ability to attend to their own needs. When these findings are considered alongside a family systems perspective, they 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. Parents do not receive enough government funding for their children, have limited access to treatments and services, and are stuck on waitlists. Additionally, some parents had not sought out support for themselves but would put the time and energy necessary into advocating for their child.

Parents identified several different sources of support that they found helpful, including professional helpers, extended family, and school and childcare programs. A Spearman's correlation was run to determine the relationship between the FSS informal subscale and the PSS informational support subscale, as well as the FSS informal subscale and the PSS emotional

support subscale. While assumptions cannot be made about the distribution of data, there were strong, positive correlations between both sets of variables which is indicative of statistically significant relationships. Parents recorded an average score of 23/44 on the PSS, with a mean emotional subscale score of 7.4/12. These results indicate that parents perceive emotional support from informal sources to be available more frequently than tangible or informational support. The need for emotional coping from informal sources, such as family and friends, is important in offering parents an opportunity to discuss their daily experiences (Derguy et al., 2015). Communication within and outside of the family can eliminate feelings of social isolation that have been heightened by the pandemic.

However, the most consistently reported source of support was their spouse or partner. Parents relied on themselves and their partner because they both intimately know what their child needs and understand how their child learns. The results of the FSS reinforce this finding, with 57.58% of parents rating their spouse or partner as the most helpful source of support. Parents found value in 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). This finding is supported in the current study, whereby parents appeared to be increasingly self-reliant due to external sources that were perceived as unhelpful. By relying primarily on themselves and their partners, parents were limiting their involvement in and minimizing negative experiences with formal services. These findings could also be attributed to the impacts of COVID-19 on the ability to seek support outside of the immediate family. Due to social distancing and stay-at-home orders, many

families were unable to access most of the services that could help them, including professionals who were part of their regular routine prior to the pandemic. Additionally, the tangible and incidental support that extended family and friends provided was no longer accessible. While some parents explicitly stated that they shared the active parenting role with their partner, other parents relied on themselves and their spouse because they did not know who to turn to or had no one else to physically rely on. Unlike previous research (e.g., Luther et al., 2005; Mackintosh et al., 2005), the parents in the current study did not mention support groups as a large source of information or support. Despite the reported benefits of support groups—a safe place to discuss difficulties, engage in practical coping, and gain knowledge—parents did not appear to seek out this source of support. Only 7.41% of parents who responded to the FSS rated parent groups as "very helpful" or "extremely helpful." A small number of parents said that they had relied on other parents who have gone through the same thing, but this required additional time and effort to access. It was hard for these parents to seek out support from others during COVID-19, but the psychological, emotional, and informational support that parent groups provide should not be overlooked.

A notable theme resulting from this current study that highlights how parents perceive the accessibility, availability, and effectiveness of support is the barriers to service access. The service system was viewed as inaccessible in many ways and has been manifesting as a combination of 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.

Parents discussed limitations surrounding funding, guidance from professionals, waitlist times, and a lack of needs-based assessments. Similar to 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. Not only did the service system did not support parents, but it also did not support their children. Parents perceived the Ontario service system to work within a "framework that limits what it provides and views ASD as a behavioural disorder that can be fixed, rather than a neurodivergence" (#48). As Luther et al. (2005) and Meadan et al. (2010) found, parents assume large responsibility for meeting their child's needs, putting their own needs aside and sacrificing a part of themselves. Similarly, parents in the current study have been working to advocate for a needs-based assessment program in Ontario that considers the individual needs of each child and family. These parents were concerned with how the government had not provided adequate family services, health care access, or included parents in the decision-making process. The criticism and response from parents surrounding the proposed OAP program will be discussed further in the recommendations and implications for future research section.

Furthermore, Stahmer et al. (2019) found that it is often factors such as race, education, and income that 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. Despite parents who were more likely to possess the resources and knowledge to access services, they experienced additional barriers that continued to limit participation in services. Many parents discussed financial constraints, which could be the result of a disconnect between how much funding is available and the actual cost of ASD services. Children under six can receive up to $20,000 per year and children over

six can receive $5,000 per year; however, intensive therapies such as ABA can cost anywhere from $50,000 to $80,000 per year (Sharratt, 2019). This has left parents covering significant out-of-pocket expenditures. Even parents who were employed had difficulty accessing services, which alludes to barriers in service access that extend beyond income-based assessments.

As mentioned in the results, data were collected from parents regarding their important support needs and their unmet needs through the FNQ. In the current study, the needs rated as "important" or "very important" by parents related to professionals working with their children. These items included parents needing their questions to be answered honestly, needing to be well-educated to be an effective decision-maker, needing to be shown respect by professionals, and having a professional to turn to for advice. In comparison, the needs rated as "partly met" or "unmet" were related to the parents themselves (e.g., "I need to spend time with my friends, "I need to get enough rest or sleep"). Parents consistently endorsed needs relating to formal services and focused on finding consistent, accessible supports from knowledgeable professionals for their child. These findings could indicate parents' need for professionals to assist with service navigation and access to credible information, materials, and guidance (Alves & Maich, 2019; Derguy et al., 2015; Siklos & Kerns, 2006). Parents also responded to the URN, whereby the relatively strong mean score (35.37/60) provides some indication that parents perceive their needs as being met. The URN asks parents about their desire or need for more support to manage the physical, behavioural, and emotional concerns of caregiving. In line with the results of the FNQ, it could be that parents are more concerned about the needs of their children and overlook their own needs, resulting in a more favourable outlook on their unmet needs.

The priorities reported by parents underline their own need for support from professionals (Derguy et al., 2015). 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 in turn, support the various facets related to parenting. Therefore, professionals need to provide a family-centred approach to services, particularly because parental involvement has been shown to increase positive affectivity (Derguy et al., 2015). Parents in the current study felt that there was not enough importance placed on providing early interventions and treatments or involving parents in the process. Furthermore, these parents focused the majority of their time and energy on locating resources and parents likely felt that the service system, and particularly professionals, were not adequately providing the necessary support. Similar to the findings of 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. This is an interesting finding given the current situation within Ontario, where parents are advocating for an inclusive, needs-based approach to ASD service delivery. Formal support, such as the OAP, is a fundamental resource that provides funding and access to treatment for families, but 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. Without government funding and the ability to access treatments, parents did not think their child would have made progress nor would their family have made the necessary connections.

Furthermore, when parents were asked to rate the helpfulness of support in the FSS, professional agencies (e.g., public health, social services, mental health services) were among the lowest-rated sources. Only 12.7% of participants rated professional agencies as "very helpful" or

"extremely helpful" in supporting their needs. Despite this, parents cited positive experiences with professional helpers (e.g., social workers, therapists, teachers). The contrast between professional agencies and professional helpers tells us that while parents struggle with accessing available government services, parents view social workers and therapists as integral in supporting their needs. While information was not collected on *how* parents accessed these sources of support or the specific form of support that professional helpers provide, parents found support workers through community-based programs such as Community Living and searched for respite care outside of government agencies. These services provided parents with a break and time to themselves, which was viewed as helpful. Due to COVID-19, many families were unable to access respite care or continue regular visits with support workers but recognized how their families were missing the benefits these individuals provide. There were a few parents who found respite care workers to be financially out of reach and school-based helpers to lack adequate knowledge of ASD.

A main objective of the current study was to understand how parents perceive the role of social support within the framework of role theory. The current findings demonstrate support for a role theory approach to understanding the experiences of these parents, with participants sharing that they were experiencing an increase in multiple 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 are responsible for navigating the educational, social services, and health care systems for their children (Desmarais et al., 2018). Parents attain multiple roles within the home (e.g., educator, advocator, caregiver) due to a discontinuity of support from formal services and the time spent

between these roles highlights the resources and support needed for parents to navigate their multiple and demanding roles. 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' normal routine, which means that parents were tasked with adapting to working from home while simultaneously helping their children adapt to remote learning. The impacts of overlapping roles were seen by participant #52 who said that: "I am working from home and our children are home virtually [for school] making home life more chaotic than usual… and we are unable to access services due to closures." Parents' support needs have been exacerbated by COVID-19, yet the complex arrangements needed to successfully balance work and home responsibilities have diminished. Parents cannot continue to sustain multiple demanding role responsibilities as they are already feeling stressed, overwhelmed, and burnt out.

Similar to previous research on parents of children with ASD, questions were asked about parental mental health. In the current study, the WHO Well-Being Index was used to better understand how parents have been coping during COVID-19 and specifically, the two-week period prior to completing the survey (World Health Organization, 1998). It is important to note that this scale was used to understand parental mental health in relation to their current life circumstances and not in relation to their child or their child's ASD. This study aimed to move away from the developmental perspective that frames the child as a stressor and focuses on external sources that can contribute to stress, such as barriers to service access. Parents who responded to the WHO Well-Being Index received scores that are indicative of poor mental well-

being; the results showed that 71.4% of participants received a total score of 13 or less. The high percentage of parents who indicated that they were experiencing poor mental health could be attributed to the result of familial, social, and political changes that are not directly attributed to their child's ASD. At the time of the survey, public health restrictions were still in place for residents of Ontario due to COVID-19—these restrictions included social distancing measures, lockdowns in some areas, and lack of access to face-to-face services. These ongoing restrictions resulted in parents working from home, children engaging in remote learning, changes to service delivery, and added responsibilities that would collectively contribute to overall well-being. Additionally, these results can be compared against previous literature that indicated parents of children with ASD engage in more responsibilities and experience increased barriers than parents raising neurotypical children (Hoogsteen & Woodgate, 2013; Pickard & Ingersoll, 2016)— factors that have been heightened during the pandemic.

Nevertheless, parental mental health cannot be fully understood without considering the results of the Brief Resilience Scale (BRS) for participants in the current study (Smith et al., 2008). Although 71.4% of parents indicated that they were experiencing poor mental well-being, the relatively strong mean score (3.28/5) on the BRS provides some indication of resilience among parents of children with ASD. Making meaning out of adversity is a key process in family resilience (Bayat, 2007), which was seen in the parents studied. The families not only reported positive scores on the BRS, but they also articulated lessons learned as a result of their child's ASD and COVID-19. Parents' meaning-making resulted in a positive outlook of life for some families, while others had an appreciation for spending more time as a family unit. As reported by Smith et al. (2008), the ability to recover from adversity may be more important than the ability to avoid certain life circumstances, and resources such as social support or active

coping may help facilitate the ability to recover. With these capabilities in mind, it can be assumed that while parents are currently experiencing poor mental health, many parents recognize their resiliency. The ability to recover from adversity was seen by parents who described the difficult experiences of COVID-19 while simultaneously acknowledging that these feelings are temporary. As participant #41 said: "it has been a hard year, but it's getting better… we will be okay." Previous research results have shown that despite the increased stress that parents of children with ASD experience, many are still able to successfully manage in the face of adversity (Peer & Hillman, 2014). Additionally, the role of social support is regarded as a resilience factor, often negating the impact of adversity and promoting stability for families (Peer & Hillman, 2014). The relationship between low well-being and high resilience could also be explained by the strait-trait theory, which outlines that human behaviours and emotions depend on the characteristics of the person (traits), characteristics of the situation, and the interaction between the two (Steyer et al., 1999). Together, these factors create a psychological state that can vary across time and context. In the current study, parents have been exposed to different situations, such as COVID-19, that have increased feelings of stress, anxiety, worry, and fatigue. These emotions and feelings are temporary as reflected by their low well-being scores, while resilience is a stable and enduring characteristic of these parents. It is important that current parental well-being is not mistakenly attributed to their internal characteristics but is instead seen as a reaction to external circumstances.

Previous researchers have found that 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 findings of the current study suggest that despite reporting feelings associated with poor mental health, these parents were actively adopting healthy coping

mechanisms. 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 for Future Research

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 a comprehensive overview of the factors influencing parents' perception of support; however, there are several recommendations for key stakeholders including future researchers, the Ministry of Children, Community and Social Services (MCCSS), and ASD service providers.

As many parents perceived support in relation to the support their child receives, these conversations involved the OAP. Findings of the current study suggest that, overall, parents 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. This definition of ASD should be considered by the MCCSS, service providers, and the OAP advisory panel. 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 because the 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.

With this in mind, the Ontario government, service providers, and future researchers should work to increase parental involvement in the diagnosis, assessment, 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 a service system 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.

The results of the current study reinforce that there are still gaps between what parents need from ASD services and what is actually available across Ontario. The findings suggest the need to further support parents in all realms of the formal service system—education, health care, and social services. This includes, but is not limited to, continued financial investment in ASD services and programming, removing age-based limitations on funding, and reinforcing a foundational family focus on service delivery. These findings are useful for the Ministry of Children, Community and Social Services as it highlights the voices of Ontarian parents in terms of their concerns, critiques, and suggestions for supporting their families. It would be beneficial

for the Ministry to update the OAP Advisory Panel to include parents and members of the

Autistic community and emphasize the importance of these perspectives. It is not only necessary

to consult with this community during the development of this program, but it is crucial in

addressing the support needs of parents of children with ASD.

In terms of future research objectives, researchers should focus on participatory research

and community engagement to better understand the needs of parents as the new OAP is

implemented. Due to COVID-19, this research design was unable to accommodate qualitative

interviews or direct involvement with the Autistic community. Additionally, ASD research

should be done within a family systems framework that is inclusive of the bidirectional

relationship between children and parents. Understanding this relationship is crucial when

identifying the support needs of parents, as parents in the current study are focused on a family-

centred approach to care. Further research is needed to determine the appropriate mechanisms to

build relationships and rapport with these parents. Current studies mainly involve the

experiences of White, well-educated parents, whereas future research should consider the

intersection of diverse identities to ensure that the future OAP is inclusive of Ontario's

prominent diversity. By incorporating these gaps into future research and policy development,

the Ontario government can work towards enhancing parental involvement in ASD services and

eliminating the barriers to an accessible, equitable service system.

Limitations and Strengths

Within the context of the current study, there are both strengths and limitations to the

study design. 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). Furthermore, small sample sizes can undermine the internal and external validity of the study. With only 35 participants, this research study had an insufficient sample size to produce valid statistical results. In terms of quantitative analyses, this study utilized primarily descriptive statistics to supplement the qualitative analyses and results; the only true statistical test was Spearman's correlation, which should be interpreted with caution.

Coinciding with the small sample size, a second limitation is the representation of participants in this study. The majority of the participants (91.4%) identified as women and only 8.6% identified as men; however, this is a common limitation in ASD research, whereby it is assumed that mothers are the primary caretakers of children with ASD (Boyd, 2002; Bromley et al., 2004; Siklos & Kerns, 2006). When considering the impact of support resources for parents, 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 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. 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).

A third limitation to this study was the use of certain scale questions and open-ended questions included in the survey. To build upon previous research on the different needs of parents and the current social, financial, and personal constraints that they may experience, the Impact on Family Scale (IFS) and the Family Needs Questionnaire (FNQ) were included. Both of these scales were adapted to fit within the theoretical and philosophical frameworks of the study, but it should be acknowledged that these surveys have previously been used to reinforce the idea that a child with ASD is a stressor to family life. Some of the language used within the survey was in line with previous research which could have been altered to capture the intended study. Potentially ableist terms and deficit-based discourse were used in this thesis that commonly appear in previous ASD research but have non-ableist alternatives (Bottema-Beutel et al., 2021). For example, replacing 'comorbid' with 'co-occurring' and asking parents to describe their child's level of support, rather than providing a restrictive list of options. This limitation was explained by a parent who left an additional comment at the end of the survey:

> As an autistic adult, I'm concerned about the tone of the study which casts the autistic child as a burden who brings down the mental and physical well-being of those around them. Our family subscribes to the social model of disability by which we are disabled by an ableist culture that feels that our needs are special or that our differences are negative.

Due to time constraints, I was unable to consult with members of the Autistic community before publishing the survey. In the future, researchers should focus on including Autistic adults and families with lived experiences to develop a study that minimizes ableist language and increases autistic self-advocacy (Woods, 2017).

The final limitation was the length of the survey. This study included multiple scale questions and open-ended questions that required more detail from participants than if the study was solely quantitative. Qualtrics collected the duration (in seconds) that each participant took to respond to the survey; the mean time was 63.18 minutes (range: 12.7–537.9) or about an hour. The length of the survey may have increased the burden placed on participants and decreased their willingness to complete the survey. It is possible that when completing longer questionnaires, participants are more likely to become desensitized to answering personal questions and omit detail (Kost & Correa da Rosa, 2018). Multiple open-ended questions can also be seen as a strength, as the mixed-methods research design increased the comprehensiveness of participants' answers. However, response and completion rates could be attributed to the opportunity to enter an incentive prize draw at the end of the survey.

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.

Another notable strength of the current study was its focus on families of children with ASD in an Ontario context, with a focus on the Ontario Autism Program and COVID-19. Given the political timeliness of discussions around the OAP, this research is beneficial for providing insight into the ways that the current service system does not fit with families' needs. Previous literature has not collected updated information on parents' perception of the OAP; thus, this study provided participants with the opportunity to voice their concerns with the OAP and the role that current programming plays in their lives. This study is, therefore, able to contribute to the limited amount of evidence-based research on the availability, accessibility, and effectiveness of the OAP. The information provided by participants demonstrates the immense role that social services play in supporting their families and can be used to shape and create a program that fits with the diverse needs of Ontarian families.

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 Ontarian families can be examined to develop support that is available, accessible, and effective.

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Appendix A – Virtual Recruitment Poster

THIS PROJECT HAS BEEN REVIEWED BY THE RESEARCH ETHICS BOARD
FOR COMPLIANCE WITH FEDERAL GUIDELINES FOR RESEARCH
INVOLVING HUMAN PARTICIPANTS (REB#20-07-020)

VOLUNTEERS NEEDED

Are you the parent of a child with autism?

WE WANT TO HEAR FROM YOU!

We want to hear both parents' perspectives on accessing support and learn about your experiences with Ontario autism services.

What will you be asked to do?
- You will be invited to complete a 30 minute online survey
- Enter for a chance to win $25!*

INTERESTED? WANT TO FIND OUT MORE?
VISIT: https://uoguelph.eu.qualtrics.com/jfe/form/SV_73eJOItCZ1O7iHX

If you have any questions or concerns, please contact the Principal Investigator: Dr. Tricia van Rhijn at tricia.vanrhijn@uoguelph.ca

*Each participant will have the opportunity to enter the draw for 1 of 2 $25 prizes. The approximate odds of winning are 1 in 50.

Appendix B – Recruitment Email Script

Subject line: Understanding support for parents of children with ASD study invitation

Recruitment has launched for the "**Understanding how parents of children with Autism Spectrum Disorder perceive the role of formal and informal support resources"** research study. If you are the parent of a child with ASD, we are sending this information to invite **you and/or your partner** to participate in this exciting study.

This project is collecting information to deepen our understanding of the impacts of support resources for parents of children with ASD. Evidence from previous research suggests that parents generally perceive formal and informal support resources as a beneficial mechanism in successfully adapting to parenting a child with ASD, but experience barriers to coordinated and family-centred care. This survey will be used to examine how parents of children with ASD view the effectiveness, availability, and accessibility of support resources in Ontario and where they seek out this support. We believe that this research is important and can help to better understand how current resources support parents' needs. Given the current global climate, it is also important to recognize the impacts of the coronavirus disease (COVID-19); this research will seek to further gather parents' perspectives on the role that COVID-19 has played in their lives.

If you are a parent of a child with ASD between the ages of 6 and 17, live in Ontario, and see your child on a regular basis, you and/or your partner are invited to participate in this project. Parents who have their child in their care less than 50% of the time are not eligible to participate.

You will be asked to complete one online survey each. **Each online survey will take approximately 30 minutes to complete.** You can skip any questions you do not wish to answer or choose "I prefer not to answer." As a thank you for your participation, each participant will be given the opportunity to enter into an incentive prize draw to win $25. For every 50 participants, there will be 1 winner drawn (1 in 50 chance of winning). After you complete the survey, you will be able to enter your name and email address into a secondary survey. This data will be deleted following project completion.

If you are interested in participating and would like to volunteer, please see the link below. This link will take you to the online survey, where your participation will be discussed in detail and you will be asked to give your consent to participate:

https://uoguelph.eu.qualtrics.com/jfe/form/SV_73eJOItCZ1O7iHX

If you have any questions or concerns, you may contact the Principal Investigator, Tricia van Rhijn, or myself, the Student Co-investigator, using the contact information provided below. This project has been reviewed by the University of Guelph Research Ethics Board for compliance with federal guidelines for research involving human participants (REB# 20-07-020). You do not waive any legal rights by agreeing to take part in this study.

If you have questions regarding your rights and welfare as a research participant in this study (REB# 20-07-020), please contact:

Manager, Research Ethics   Telephone: 519-824-4120, ext. 56606
University of Guelph   E-mail: reb@uoguelph.ca

Take care,
Kaitlyn Avery

Principal Investigator:
Tricia van Rhijn, Ph.D.
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University of Guelph Student Co-investigator:
Kaitlyn Avery, BA, MSc Candidate
Department of Family Relations and Applied Nutrition
University of Guelph
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You are invited to participate in a study titled, **"Understanding how parents of children with Autism Spectrum Disorder perceive the role of formal and informal support resources."** The purpose of this letter is to provide you with the information you require to make an informed decision on participating in this research. The researchers involved in the study are listed below and contact information is provided, should you have any questions or concerns about the research.

Principal Investigator:
Dr. Tricia van Rhijn, Associate Professor, Family Relations and Applied Nutrition (FRAN), University of Guelph, 519-824-4120 ext. 52412 or tricia.vanrhijn@uoguelph.ca

Student Co-Investigator:
Kaitlyn Avery, MSc student, Family Relations and Applied Nutrition (FRAN), University of Guelph, 226-235-4110 or kavery@uoguelph.ca. I am a Master's student in the Department of Family Relations and Human Development and the information I am collecting will be used in my thesis.

PURPOSE OF THE STUDY
The purpose of the proposed study is to investigate the self-reported needs of Ontarian parents of children with Autism Spectrum Disorder (ASD). This study seeks to develop an understanding of how support resources impact parents and how they view the role, availability, accessibility, and effectiveness of support in their lives.

PROCEDURES
You are being invited to take part in the study because you are a parent of a child with ASD between 6-17 years of age. Parents who have their child in their care less than 50% of the time are not eligible to participate. If you choose to participate in this research project, you and/or your partner will be asked to complete **one online survey each**. The survey will take approximately 30 minutes to complete. You will complete the online survey which will ask both open and closed-ended questions and demographic questions and require participants to respond to scale measures. Examples of questions include: "What are your expectations when seeking support," and "Indicate how helpful each source of support has been to your family during the past 3 to 6 months." The questions will investigate the primary objective of this research study (i.e., to assess the self-reported needs of parents and understand how they perceive the role and availability of support resources). All completed surveys will be used in the study (i.e., those that went through all of the questions and submitted their surveys). All surveys that are 95% or greater completed will be retained and all others will be deleted.
POTENTIAL BENEFITS AND RISKS

When completing the survey, some of the questions deal with sensitive topics and personal feelings and you could feel some discomfort when answering them. You are free to answer in as much depth and detail that you feel comfortable sharing. There will be no direct benefit to participants, but we believe you may find the experience helpful in terms of sharing your experiences with the Ontario service system and the impacts of support on your life. This research will further benefit autism research, as Canadian contexts are largely understudied. There may also be societal benefits, as this study may lead to a better understanding of the role that support plays in your family's life. Positive coping mechanisms and support services may also be identified.

INCENTIVES TO PARTICIPATE
As a thank you for your time, you have the opportunity to be entered into a prize draw for the chance to win $25. For every 50 participants, 1 winner will be chosen. The researchers hope to recruit 100 people, making your chance of winning the prize 1 in 50 – but this number is subject to change. If you choose to enter the draw, you will be directed to do so at the end of the survey, and you will be asked to provide your full name and email address in order to receive payment.

The next business day after the survey closes, the data for the incentive prize draw will be downloaded into an Excel spreadsheet. The participants will be numbered. The random integer generator on www.random.org will be used to select the 2 winning numbers. The 2 selected numbers will be matched to the participant numbers and they will be contacted by email that they were selected. Winners will receive the initial notification, and should they not respond within 7 days, one follow-up email will be sent giving them a 7-day window to respond. If they fail to respond, we will draw another winning number following the procedure outlined above.

This money will be e-transferred to you at the email address provided. Records of all e-transfers will be provided to the University of Guelph Financial Services. This record will include participant email addresses. Only the Principal Investigator, Student investigator and the University of Guelph Financial Services will have access to the identifying information. It will be stored on a password-protected computer until the winners have received their money. Once the winners have received their incentive prize, the identifying information will be deleted and only Financial Services will have a record of the transaction.

RESEARCH RESULTS
The research results will be published in Kaitlyn Avery's Master's thesis and shared with the Department of Family Relations and Applied Nutrition; however, results can be made available to you by contacting the Principal Investigator, tricia.vanrhijn@uoguelph.ca, and requesting a copy. The research results may also be disseminated in an academic journal or as a conference and poster presentation. You may also receive a copy of any publication resulting from this research by emailing the Principal Investigator and requesting a copy be provided to you.

CONFIDENTIALITY

To ensure confidentiality, your name will not be collected by the survey and your data will be used for this study only. You will not be asked to reveal any identifying information while completing the survey—such as name, location, or contact information. It is recommended that in order to protect your anonymity, you should not provide any information in the open-ended survey responses that could identify yourself or others. The collected survey data will be secure and stored on a password-protected, encrypted website (Qualtrics.com). Qualtrics uses the same encryption type (SSL) that online banking sites use to transmit secure information and IP addresses will not be collected. Please note that confidentiality cannot be guaranteed while data are in transit over the internet. Once downloaded from Qualtrics, data collected during this study will be stored on a password-protected laptop computer with full disk encryption, only available to the research team of this project (i.e., the Principal Investigator and the Student Co-investigator).

Following project completion, the electronic data collected will be shared in the student co-investigator's Master's thesis. While verbatim responses may be used for any reports, presentations, or articles based on this data, any potentially identifying information will be removed from the quotation to ensure anonymity.

We recommend that you complete the survey in one sitting and then follow the instructions below to further protect your privacy; otherwise, other individuals with access to your computer may be able to view your survey responses.

If you would like to further protect your privacy you can:
1. Clear the browsing history
2. Clear the cache
3. Clear the cookies
4. Clear the authenticated sessions
5. LOG OFF

If you are using Internet Explorer, going to Tools and selecting Delete Browser History can accomplish the first 4 steps. Your application may have a similar system.

PARTICIPATION AND WITHDRAWAL
You can choose whether to be in this study or not. Your decision to participate in the study will not affect any services you receive from the organization(s) that forwarded you the invitation to participate. If you decide to participate in this study (by clicking the 'Next' button below and answering the questions), you may withdraw at any time without consequences of any kind:

1. While filling out any part of the online survey, you may choose not to submit your survey by simply closing the survey page on your web browser.

Throughout the survey, you may also refuse to answer any questions you don't want to answer (either by skipping that question or by selecting the 'I choose not to answer' option) and remain in the study. You will still have the opportunity to enter your email in the prize draw even if you choose to withdraw from the study.

Should you wish to withdraw from the study, your information will not be saved, and we will not have access to it. You can withdraw from this survey at any time by closing your browser. Data from incomplete surveys will be discarded. Once you submit the survey, you cannot withdraw from the study because your survey cannot be identified, and the data collected is anonymous.

We encourage you to keep a copy of this consent information for your records. For a printable copy of this consent information, please click here: **print button.**

RIGHTS OF RESEARCH PARTICIPANT
You are not obligated to answer any questions that you do not want to. Participation in this study is voluntary. You may refuse to participate, refuse to answer any questions, or withdraw from the study with no consequences or effect on you.

This project has been reviewed by the University of Guelph Research Ethics Board for compliance with federal guidelines for research involving human participants (REB# 20-07-020). You do not waive any legal rights by agreeing to take part in this study. If you have questions regarding your rights and welfare as a research participant in this study (REB# 20-07-020), please contact:

Manager, Research Ethics   Telephone: 519-824-4120, ext. 56606
University of Guelph   E-mail: reb@uoguelph.ca
437 University Centre   Fax: 519-821-5236
Guelph ON N1G 2W1

By clicking the "I agree" button below, you are consenting to take part in the study.

Appendix D – Data Collection Tools

Online survey questions including source and items

Source	Items
Research Questions: 1. To what extent do parents perceive support resources to be effective in supporting their needs? To what extent do they perceive them as available and accessible? 2. How have recent changes to the Ontario Autism Program impacted parental perception of available and accessible supports? 3. What role has COVID-19 played in the availability and effectiveness of service delivery?	
Open-Ended Survey Questions – Service Use	
Researcher Created	1. Please describe the interventions or treatments that your child currently receives. 2. What changes have there been to your life since your child was diagnosed? 3. Do you feel that you receive the supports you require to best support your child? Please explain 4. What type of support/who do you rely on the most when faced with difficult or adverse situations? 5. Do you find it easy to seek out support or ask for help? If not, why? 6. Is there anything preventing you from getting support? If yes, what? 7. Are there any supports that you require but have been unable to access? If yes, please describe. 8. What are your expectations when seeking support?
Influences – Ontario Autism Program (OAP)	
Researcher Created	1. Are you currently using the Ontario Autism Program? (if not, explain why) 2. If applicable, how much funding does your child receive from the OAP? 3. How has the program impacted your life? (e.g., ability to find treatment for child, ability for time alone, time to do things for yourself, etc.) 4. Please describe any concerns you have with the program (if any). 5. What could the OAP do to better meet your needs and your family's needs?
Influences – COVID-19	
Researcher Created	1. What aspects of your life have changed since COVID-19 began? 2. What changes occurred to your support services due to COVID (e.g., loss or cancellation of services, change to remote delivery)? Please explain. 3. Please explain the ways that this time has affected your well-being or mental health. 4. What have you been doing to cope with life during COVID-19?
Scale Measures	
Family Support Scale (Dunst et al., 1984) Indicate how helpful each source has been to your family during the past 3 to 6 months. If a	1. My parents 2. My spouse or partner's parents 3. My relatives/kin 4. My spouse or partner's relatives/kin 5. Spouse or partner 6. My friends 7. My spouse or partner's friends 8. My own child(ren) 9. Neighbors 10. Other parents

source has not been available to your family, circle the NA (Not Applicable) response:	11. Co-workers 12. Parent groups 13. Social groups/clubs 14. Church members/minister 15. My family or child's physician 16. Early childhood intervention program 17. School/daycare center 18. Professional helpers (social workers, therapists, teachers) 19. Professional agencies (public health, social services, mental health)
Family Needs Questionnaire (Kreutzer et al., 1988) Rate the following statements in terms of how important they are to your life and the extent to which it is being met:	1. I need to be actively involved in my child's treatments and therapies 2. I need to be well-educated about my child's disorder in order to be an effective decision-maker regarding the needs of my child 3. I need to be shown that my opinions are used in planning my child's treatment, therapies, or education 4. I need to have a professional to turn to for advice or services when my child needs help 5. I need to have help from other family members in taking care of my child 6. I need to be told why my child acts in ways that are different, difficult, or unusual 7. I need to have time to spend alone with my other children 8. I need to be shown what to do when my child is acting unusually or is displaying difficult behaviors 9. I need to have information regarding my child's therapeutic or educational progress 10. I need to have help in deciding how much to let my child do by him/herself 11. I need to have help with housework 12. I need to have counseling for myself and my spouse/partner 13. I need to get enough rest or sleep 14. I need to get a break from my responsibilities 15. I need to spend time with my friends 16. I need to be told if I am making good decisions about my child 17. I need to discuss feelings about my child with a parent who has a child with the same disorder 18. I need to be reassured that it is not uncommon to have negative feelings about my child's behaviors 19. I need help dealing with my fears about my child's future 20. I need help in remaining hopeful about my child's future 21. I need to have my questions answered honestly 22. I need to be encouraged to ask for help 23. I need to be shown respect by the professionals working with my child 24. I need respite care for my child 25. I need to have time to spend alone with my partner 26. I need to have the professionals working with my child to speak to me in terms I can understand
Perceived Support Scale (Krause, 1995; Krause &	1. How often has someone provided you with some transportation? 2. Pitched in to help you do something that needed to get done, like household chores or yard work? 3. Helped you with shopping?

Borawski-Clark, 1995) Using the scale, indicate how often the following statements apply to you:	4. How often has someone been right there with you (physically) in a stressful situation? 5. Comforted you by showing you physical affection? 6. Listened to you talk about your private feelings? 7. Expressed interest and concern in your well-being? 8. How often has someone suggested some action you should take in order to deal with a problem you were having? 9. Given you information that made a difficult situation easier to understand? 10. Helped you understand why you didn't do something well? 11. Told you what they did in a stressful situation that was similar to one you were experiencing?
Unmet Resource Needs (King et al., 2013) Please indicate your agreement to the following statements:	1. I needed a resource/service to help with caregiving, but did not have it 2. I needed services to help with my own emotional response to caregiving, but did not have them 3. I needed services to help with my emotional response to caregiving, but was reluctant to use them 4. We needed services to help with our child's emotions, but did not have them 5. We needed services to help with our child's behavioral response, but did not have them 6. We needed services to help with our child's physical recovery, but did not have them 7. I did not know what kind of resources and/or services would help with a problem 8. I did not know where to get help finding resources and/or services that we needed 9. I usually tried to get a resource and/or service that I thought we needed 10. I wished I could use the internet for help with resources, but I did not know how 11. I wished I could use the internet for help with resources, but I did not have access to a computer 12. Our financial situation prevented us from getting resources/services that we needed
Impact on Family Scale (Stein & Riessman, 1980) Please indicate your agreement to the following statements:	1. Additional income is needed to cover medical expenses 2. Time is lost from work because of appointments 3. I am cutting down the hours I work to care for my child 4. We see friends and family less 5. I don't have much time left over for other family members after caring for my child 6. We have little desire to go out because of my child's ASD 7. Because of my child's ASD, we are not able to travel out of the city 8. Sometimes we have to change plans about going out at the last minute because of my child's state 9. Travelling to the hospital is a strain on me 10. I feel like we live on a roller coaster: in crisis when my child is ill, OK when things are stable 11. It is hard to find a reliable person to take care of my child 12. I live from day to day and don't plan for the future 13. Fatigue is a problem for me 14. Learning to manage my child's ASD has made me feel better about myself 15. Because of what we have shared, we are a closer family

	16. My partner and I discuss my child's problems together 17. My relatives have been understanding and helpful with my child
The Brief Resilience Scale (Smith et al., 2008) Please indicate the extent to which you agree with each of the following statements by using the following scale:	1. I tend to bounce back quickly after hard times 2. I have a hard time making it through stressful events 3. It does not take me long to recover from a stressful event 4. It is hard for me to snap back when something bad happens 5. I usually come through difficult times with little trouble 6. I tend to take a long time to get over set-backs in my life
WHO-5 Well-Being Index (World Health Organization, 1998) Please indicate for each statement which is closest to how you have been feeling over the last two weeks:	1. I have felt cheerful and in good spirits 2. I have felt calm and relaxed 3. I have felt active and rigorous 4. I woke up feeling fresh and rested 5. My daily life has been filled with things that interest me

Researcher Created	About the Parent:
	    1. What is your age?
	    2. What gender identity do you most identify with?
	    3. Which of the following best describes your ethnic background?
	    4. What is your current relationship status?
	    5. What is the highest degree or level of education you have completed?
	    6. What is your current employment status?
	    7. What is your estimated yearly household income?
	    8. Do you live in an urban area or in a rural community?
	    9. How many children do you have?
	    10. Has one or more of your children been diagnosed with ASD?
	    11. How many children have been diagnosed with ASD?
	About the Child:
	    1. What is your child's age?
	    2. What is their gender?
	    3. What has your child been diagnosed with?
	    4. What was their age at diagnosis?
	    5. What is your child's level of functional independence (e.g., requiring support, requiring substantial support, or requiring very substantial support)?

	6. Does your child have any comorbid conditions? (e.g., one or more conditions occurring alongside your child's ASD, such as ADHD)?