

Leaving 'Em High and Dry:
An Examination of Mothers' Experiences Accessing Services for their Children with Autism
Spectrum Disorder

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ABSTRACT

Leaving ‘Em High and Dry: An Examination of Mothers’ Experiences Accessing Services for their Children with Autism Spectrum Disorder

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This dissertation reports on the results of a qualitative investigation of the experiences of mothers whose children with autism spectrum disorder were experiencing transitions into and out of adolescence. A Constructivist Grounded Theory methodology was implemented in this study. Semi-structured interviews were conducted with 78 mothers who had children between the ages of 12 and 22. Mothers’ experiences were influenced by several factors, arranged in four core categories: parent stressors (67%), services (4%), professionals (24%), and parent solutions (5%). The constructivist grounded theory process culminated with the *Parents’ Perceptions Theory* (PPT) emerging from the data. The PPT theory explains that maternal stress is elevated when services or clinical practices are *perceived* to be unhelpful. Specifically, when services or practices were perceived as not addressing the needs of the parents or child *from the mothers’ perspectives*, mothers reported higher stress. The PPT provides a new account grounded in mothers’ own experiences for the observation that mothers’ who actively receive services still report significant stress.

In Study 2, the author sought to explore whether the PPT would also be evident in the daily accounts of parenting stress in parents of younger children with ASD (ages 3-11). Semi-structured interviews about daily parenting stress conducted with 20 parents (18 mothers; 2 fathers) were analyzed for the presence of the coding scheme and the PPT that emerged from Study 1. Three of the core categories were present in the data: Parent stressors (88%), services (2%), and professionals (10%). The *Parents’ Perceptions Theory* was also reflected. Parents’ *perceptions* of the usefulness of services or clinical practices were found to influence their reported stress.

The application of Constructivist Grounded Theory across two samples of parents of children with autism spectrum disorder provided important insight into how the disconnect between parents’ *perceptions* of whether services are meeting their caregiving needs and the receipt of services contributes to parenting stress. The PPT suggests that delivery of services should be informed by regular assessment of parental perceptions of whether their needs are being met in order to provide better support to these families throughout the child’s lifespan.

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“If I have seen further, it is by standing on the shoulders of giants.” – Isaac Newton

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I contributed to the present project in several ways. In collaboration with the principal investigators, I helped in the creation and identification of the measures in Study 1. I was heavily involved with the recruitment of participants. I communicated with various government and community agencies to inform them of the project. With the principal investigators, I created and gave presentations to the professionals about the project and worked directly with them to recruit potential participants. I also recruited participants in local community events included the Autism Speaks Walk and the Salon de l'Autisme. I screened, scheduled, and conducted interviews with the participants. I did inventory of the materials for the larger project and ordered equipment. I was involved in data management and data cleaning. Specifically, at various points in the project I was responsible for uploading the collected data, backing up the data, and data cleaning. I trained research assistants on various tasks that were essential to the project including how to conduct interviews, how to transcribe interviews, coding, and data management. I was involved in the coding process and completed the theoretical coding and theory development in collaboration with Dr. Barker.

In 2018, I co-authored a published paper with Dr. Barker. The ideas in the introduction and implications of this dissertation were an adaptation and elaboration of this paper:

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Daily Stressors and Inflammation Among Parents of Children with an Autism Spectrum Disorder

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Literature Review

Julie, a young woman with an autism spectrum disorder, is a recent high school graduate. As a result of turning 18 years-old, she had to terminate her previously existing “childhood” services (e.g., school, intervention center, medical services) and is currently on waitlists for adult services. Due to the long wait and no other available services, she remains at home full-time. Being unable to afford private care for her daughter, her mother has taken a leave from work to care for Julie until she can receive services. This, in turn, has a financial impact on the family who must now rely on a sole income. It has been four months since Julie’s graduation, and her mother has observed an increase in self-stimulatory behaviors and a regression in her ability to take care of her hygiene. She has further noticed that Julie has become sadder and more withdrawn. The mother, worried about her daughter, has not been sleeping or eating well, and cries often.

This scenario is one seen too often for parents of children with autism spectrum disorders. It accurately depicts some of the difficulties experienced by children and their families during periods of transition, including the transition to adulthood. The increase in self-stimulatory behaviors and the stalled rate of skill improvement is exacerbated when there is a lack of stimulating programming for young adults that result from service gaps. The mother is experiencing increased caregiving impact, as she must fill those gaps and provide additional care for her child who is now home full-time. Throughout the current paper, the writer will avoid using potentially ableist terminology and follow the guidelines suggested by Bottema-Beutel and colleagues (2021).

Autism Spectrum Disorder

Autism spectrum disorder (ASD) is a neurodevelopmental disorder that affects 1 in 68 children, a 30% increase since 2008 (Christensen et al., 2018). Whether this reflects true increases in prevalence or changes in the screening and diagnostic process, the demands for ASD-related care are increasing. ASD is four times more common in boys than girls, and the prevalence is higher for non-Hispanic white children compared to non-Hispanic black, Asian, and Hispanic children (Christensen et al., 2018). ASD is usually diagnosed in childhood and is, according to the DSM-5, characterized by the presence of persistent deficits in social communication and social interaction demonstrated in several contexts (American Psychiatric Association (APA), 2013). This includes difficulties in nonverbal communication, social-emotional reciprocity, and in developing and maintaining relationships with others. In addition, individuals with ASD present with restricted and repetitive patterns of behaviors and interests. These behaviors can be demonstrated through stereotyped or repetitive motor movements, restricted topics of interest, hyper- or hyposensitivity to sensory stimuli, insistence on routine, and rigidity (APA, 2013). ASD encompasses a wide spectrum and the level of supports in different aspects of the individual’s daily functioning including in the social, occupational, and academic domains will vary from person to person (APA, 2013).

Stress

Stress arises from the interactions of an individual (or family) with their immediate environment and an inability to meet the demands of that environment (Folkman & Lazarus, 1985). When environmental stressors are overwhelming, an individual will engage in coping

mechanisms to restore baseline functioning. However, if the coping mechanisms are maladaptive, or if they cannot meet the new demands placed on the individual, then the individual experiences stress (Folkman & Lazarus, 1985).

In the family context, any demand that creates change within the family is a potential stressor for individual family members. Stressors can impact overall family functioning and relationships within the family including: (a) the marital relationship; (b) the bond between parent and child; and (c) relationships between siblings (Hall et al., 2012). Research has shown that some families can respond well to new stressors and adjust their functioning to maintain stability (e.g., Jones & Passey, 2004). For parents of children with ASD, the child's characteristics combined with a lack of support and social services impacts their ability to manage stress. As such, these parents tend to report a lower quality of life than parents of children with other disabilities (e.g., intellectual disabilities, Down syndrome) and parents of typically developing children (Vasipoulou & Nisbet, 2016).

Parenting Stress

Parenting stress is one of the most studied experiences of families of children with ASD. It is the experience of distress that arises from the demands associated with parenting a child (Deater-Deckard, 1998). While stress is considered a normal part of life for all families, parents of children with ASD have been found to report significant distress as compared to families of children with other disabilities and typically developing children (Baker-Ericzen et al., 2005; Rao & Beidel, 2009). Ecological Systems Theory stipulates that development is influenced by the relational and contextual systems in that an individual is embedded (Bronfenbrenner, 1977; Rosa & Tudge, 2013). For example, individual well-being is influenced by family relationships, which are in turn embedded within and influenced by different contexts such as schools and formal social services. From this view, the well-being of parents of children with ASD is influenced not only by the caregiving demands associated with their child's behaviors and difficulties, but also by the services that are available to them and their child.

Parents of children with ASD experience decreased physical and mental health, poor social functioning, and lower quality of life, on average, compared with other parents (Vasilopoulos & Nesbit, 2016). Further, these parents have reported increased caregiving impact, psychological distress, decreased marital satisfaction, lower self-confidence, and increased negative emotions compared to parents of children with other disabilities and of typically developing children (McGrew & Keyes, 2014; Hayes & Watson, 2013). These difficulties can be attributed to the specific features of ASD and a lack of appropriate support and specialized services (Rao & Beidel, 2009). The child's level of functioning has also been found to impact the well-being of parents. That is, a child's difficulties in the skills related to activities of daily living (e.g., hygiene skills) is associated with decreased parental well-being, as the child is more dependent on their parents (Krakovich et al., 2016; Raina et al., 2004). Indeed, ASD characteristics appear to create the highest amounts of stress for families, as compared to other disabilities (e.g., intellectual disabilities) and typically developing children (Hayes & Watson, 2013). This may be due, in part to the fact that ASD tends to be associated with the highest scores in child behavioral problem areas compared to other developmental disabilities (Blacher & McIntyre, 2006). As a result, mothers of children with ASD have been found to report the lowest levels of well-being (Blacher & McIntyre, 2006). Parents often report feeling as though they are in a permanent state of crisis and describe facing constant daily challenges (Mount & Dillon, 2014). To accommodate their child's needs in the short and long term, parents must often

change many aspects of their lives (Hoogsteen & Woodgate, 2012). Further, when parents have more caregiving responsibilities (e.g., multiple children), they must divide their caregiving demands amongst their children. This means parents are less available to care for the child with ASD thereby increasing their stress (Raina et al., 2004).

Caring for their children extends beyond ASD characteristics in particular to include difficulties related to sleep, eating, and self-care as well as other co-occurring medical and psychiatric conditions (Galpin et al., 2017). Due to the lifelong nature of the parenting role, parents of children with ASD experience chronic parenting stress that contributes to poor physical and mental health outcomes during midlife (Barker et al., 2014). Although ASD is often thought of as a childhood neurodevelopmental disorder, ASD features typically persist well into adolescence and adulthood. Indeed, approximately 96% of children diagnosed with ASD still meet criteria for diagnosis once they reach young adulthood (McGovern & Sigman, 2005). As a result, children will often remain at home with their parents into early to middle adulthood (Seltzer et al., 2001). Moreover, even though an individual with ASD may rely less on family members as they age (e.g., can care for some of their needs), the perception of caregiving impact does not decrease (Shivers et al., 2017). That is, parents do not habituate to the responsibility of caring for their child with ASD, regardless of age (Shivers et al., 2017).

A child's behavioral difficulties play an important role in the marital adjustment of mothers of children with ASD (Benson & Kersh, 2011). Marital satisfaction has been associated with changes in the child's behavioral problems (Hartley et al., 2012). This suggests that high parenting stress may spill over into marital interactions as mothers have fewer resources to be able to avoid disagreements and increase positive interactions with their spouse (Hartley et al., 2012). An increase in parenting stress can lead to marital difficulties which decreases marital cohesion and spousal support. These marital behaviors are associated with an increase in depressive symptoms in mothers (Benson & Kersh, 2011). Further, there are differences in the impact of parenting stress on mothers versus fathers. Mothers' parenting stress and depressive symptoms appear to be higher than fathers (Davis & Carter, 2008). In young children, the most consistent predictor of parenting stress for both mothers and fathers was the child's difficulties in the realm of social skills. Mothers were most affected by their child's difficulty with self-regulation skills (e.g., sleeping, eating, emotion regulation) whereas externalizing behaviors were associated with higher stress for fathers (Davis & Carter, 2008).

Additionally, due to difficulties in obtaining services to receive a diagnosis and then accessing specialized services to intervene with the children, parents often become their child's "case manager." In this role, they become responsible for navigating the educational, social service, and pediatric health care systems to access and coordinate services for their child (Young et al., 2009). This is not an easy role as parents often face multiple barriers when attempting to access services for their child. These include difficulties obtaining referrals for specialists and specialized services, long waitlists, and limited services once the child reaches young adulthood (Howlin & Moore, 1997; Shea & Mesibov, 2009; Taylor & Seltzer, 2010). Inappropriate service interventions will add to parenting stress as they do not target the child's difficulties (Rao & Beidel, 2009). In addition, if parents are too stressed, even the best interventions will not be helpful as parents will feel as though they cannot fully commit to practical aspects of the intervention (e.g., homework, practice trials, self-monitoring; Rao & Beidel, 2009). Finally, low levels of social support have been found to be associated with increased maternal depressed mood and decreased well-being (Benson & Kersh, 2011).

Resulting from and compounding stress associated with securing supplementary services, financial stress is a common reality for these families. It is estimated that the cost of caring for a child with ASD is approximately three million dollars over the course of the child's life (Ganz, 2007). When parents are unable to access public services, they may choose to pay for essential services privately to help their child. In addition to the cost of the actual therapies, such as speech therapy, occupational therapy and applied behavior analysis, parents must often reduce their work hours to be available to bring the child to therapy and to learn the interventions (Young et al., 2009). As a result, this leads to decreased income for the family thereby increasing financial strain and ultimately parenting stress. Further, these services are not always covered by private insurance plans, so parents are paying most costs out of pocket (Young, Ruble, & McGrew, 2009). The type of insurance may also have an impact on the quality of services available. Research has shown that families who have access to private insurance, as opposed to a public regime, reported having regular follow-up, as well as less dissatisfaction with services (Newachek et al., 2000). As children age and transition from adolescence to adulthood, the costs incurred by parents multiply because there are fewer programs and aging parents require more services including respite and in-home support (Cadman et al., 2012; Ganz, 2007). Finally, lower SES has been associated with more difficult behaviors during transitions, less access to autism-related services, and a greater risk of poorer mental health and elevated parenting stress (Liptak et al., 2008; Taylor & Seltzer, 2010; Zablotsky et al., 2013).

In light of all of these stressors, caregiver perceptions are an important aspect of parenting stress that should be assessed. Parents' perspectives on their child's behavior, lack of respite care, and lack of sleep have all been found to have an impact on caregivers' physical health (e.g., Murphy et al., 2007; Myers et al., 2009). Parents have reported the following issues to be especially stressful: long-term planning for living accommodations; planning for emotional and social support; creating opportunities for their child to build friendships; taking care of their own needs; making decisions about future home and community accommodations; being apart from their child; wills and guardianship; and dealing with professionals (Minnes et al., 2007). Further, parents' negative perceptions on their own aging mediates the relationship between parent health and parental depression (Minnes et al., 2007). Understanding parents' perspectives in these aspects is important. If we want to provide services to support them, we must understand what parents and their children need, and create the necessary services to help alleviate their stress.

Service Access and Parenting Stress

While there is a wealth of research confirming that these parents are stressed, little research has examined the professional practices and services that are beneficial in supporting parental well-being throughout their child's life. Parents of children with ASD have service needs that start during the diagnostic period and last well into adulthood. These needs range from obtaining a diagnosis and subsequent therapies (e.g., speech therapy, behavioral therapies) to transition services when the child graduates from high school (Crane et al., 2016; Shattuck et al., 2012; Taylor & Seltzer, 2010).

While one would think that access to services would help buffer the impact of stress and perhaps lead to a better quality of life, this does not seem to be the case (Vasilopoulou & Nisbet, 2016). Children with ASD require services from multiple systems including speech and occupational therapy as well as special education services (Carbone et al., 2010). Parents have difficulty finding appropriate services providers (Shattuck et al., 2012). These unmet service

needs (both perceived and real) contribute to caregiver impact (Cadman et al., 2012). Further, parents struggle with the excessive bureaucracy related to requesting and receiving services (Preece, 2014).

Significant contributors of parent distress include difficulty navigating and accessing services, coordinating and receiving care from multiple agencies and professionals, and having no centralized person or place from which to obtain information (Cadman et al., 2012; Hodgetts et al., 2017). Further, fragmented services tied with constantly having to repeat their child's history is also associated with decreased well-being (Hodgetts et al., 2017). Parents must continually "fight" for services, creating an adversarial relationship with service providers (Cadman et al., 2012; Preece, 2014). As such, parents feel misunderstood and isolated from the professionals they are working with. Parents perceive feeling blamed for their child's behaviors and report school professionals as having a limited knowledge of ASD (DePape & Lindsay, 2015).

As children age, parents become more concerned about their child meeting important life milestones such as moving out and finding employment (DePape & Lindsay, 2015). However, residential care is difficult, if not impossible, to access and becomes an important concern for parents who do not want to rely on their other children to take care of their child (Gray, 2002). Overall, parents appear to be more frustrated by service level characteristics (e.g., access to care) than by practitioner level characteristics (Hodgetts et al., 2017).

The present studies in this dissertation will examine mothers' experiences in accessing services for their children with ASD. Specifically, the studies will investigate the stressors experienced by parents and the practices that helped or hindered them while accessing and using services. This study will investigate parents' perceptions of the process to better understand the impact of these services and practices on their reported stress levels.

Transitional Periods

Transitions are difficult for families of children with ASD as these periods are often associated with uncertainty and change in services. Stress and caregiving impact seem to be the highest during certain developmental milestones (e.g., following a confirmation of an ASD diagnosis; McGrew & Keyes, 2014; Stuart & McGrew, 2009). In the following sections, the existing literature on two specific transitional periods are reviewed: (1) following the child's diagnosis and (2) during the transition from high school to adulthood.

The Diagnostic Process

Parents are often the first to observe ASD symptoms and do so much earlier than when the child receives their diagnosis. On average, parents become concerned about their child's development between 17 and 24 months of age (Baghdadli et al., 2003; Chawarska et al., 2007; De Giacomo & Fombonne, 1998; Gray & Tonge, 2001). Parents' concerns often emerge as a result of an apparent slowing down of development, lack of progress in development, or loss of a previously acquired skill (Siperstein et al., 2004). A regression is reported by parents in 10-50% of cases and involves deterioration in language (e.g., loss of words or vocalizations), non-verbal communication (e.g., loss of eye contact, pointing), or loss of pretend play skills (Davidovitch et al., 2000; Luyster et al., 2005). These regressions were sometimes preceded by a period of "normal" early development (Martinez-Pedraza & Carter, 2009). This may lead parents to delay formal evaluation of the child as they may wait to see if the child will experience a new sudden burst of rapid developmental changes. Further, the child may also have considerable strengths in

a particular domain causing parents to overlook significant deficits in other areas of the child's life (Martinez-Pedraza & Carter, 2009).

The diagnostic process can be a demanding and powerfully emotive experience for families (Avdi et al., 2000). Parents must overcome many obstacles to obtain the diagnosis and are given abundant amounts of information. Having noticed their child's difficulties, parents often seek out professional help (Martinez-Pedraza & Carter, 2009). The pre-diagnostic period usually signifies the parents' entry into the social service system. The stage during which the child's behaviors are explored and the diagnosis is confirmed is a difficult time for parents. Parents experience frustration prior to the confirmation of the diagnosis and there are significant delays in obtaining a definitive answer (Howlin & Moore, 1997). The process begins when parents share their concerns about their child's development with their pediatrician. This period is long and complex and can sometimes result in a wrong diagnosis (DePape & Lindsay, 2015). Research has shown that physicians often do not take parent concerns into account, thus delaying the next step in the process (Sices et al., 2004). Multiple referrals are often required before the parents can consult a specialist (Howlin & Moore, 1997).

The waitlists to meet with an ASD diagnostician are long and parents must wait for extended periods of time before beginning the diagnostic process (Shea & Mesibov, 2009). Further, families experience significantly longer delays when their children are high functioning (Howlin & Asgharian, 1999). On average, parents usually encounter a delay of 3.5 years between their first concern and receiving a diagnosis (Crane et al., 2016). Children are typically diagnosed around the age of 36 months for children with autism, and around 7 years of age for children with an Asperger profile (Mandell et al., 2005; Soke et al., 2017). This is especially problematic as early intervention programs are the most effective in teaching skills and managing behaviors, especially when started at a young age (Mandell et al., 2005; Soke et al., 2017). As such, these delays increase family stress and hinder the start of intervention programs for the child with ASD.

Taken together, these findings highlight several important issues. As physicians are the first point of access, more training is required to help them identify the early symptoms of ASD in young children. Further, more psychologists and diagnosticians are required to help speed up diagnostic processes and service access. Finally, collaboration between parents and professionals is essential as parents are often the first to notice problems and regressions in development.

Transition to Adulthood

The transition from adolescence to adulthood is another important period for parents of children with ASD. Parents experience moderate stress during this transition (Yu et al., 2018). It is a time of heightened opportunities, but also new risks (Blacher, 2001). Challenges are experienced for the individual, the family, and the social service system (Blacher, 2001). This is especially the case for individuals with ASD as postsecondary and employment opportunities are often limited (Schall et al., 2006). Indeed, transitions outcomes have been found to be worse for students with ASD than students with other disabilities (Shattuck et al., 2012).

Previous research has shown that the transition processes in schools do not meet necessary standards, despite parental efforts to change things (Snell-Rood et al., 2020). High schools are insufficiently addressing the needs of adolescents with ASD as existing programs are ineffective and transitions services are lacking in most schools (Kurcharczyk et al., 2015). Parental involvement in transition planning is limited. In fact, 40% of parents stated that their child's Individualized Education Plan (IEP) objectives were determined by school professionals

without their input (Cameto et al., 2004). Further, parents are often not informed about the transition planning process, including the options available for postsecondary or employment opportunities after high school (Cameto et al., 2004; Snell-Rood et al., 2020). Ineffective transition planning can lead to increased stress among parents who attempt to be active in their child's transition and future success (Yu et al., 2018). As such, successful transition planning should consider parents' objectives and well-being (Wong et al., 2020).

The markers of this transition are the child's graduation from high school or equivalent educational services, as well as the exit from the pediatric health care system into adult care. As their children finish high school, families lose entitlement to many, and sometimes all, services they were currently receiving (Taylor & Seltzer, 2010). Applying to new, more age-appropriate services becomes increasingly difficult as parents are, once again, faced with long waitlists and very few opportunities for program options that will help maintain or increase their child's autonomy (Howlin, Alcock, & Burkin, 2005). Indeed, parents find themselves having to adjust to new advocacy roles during the transition (Bianco et al., 2009; Jobe & Glidden, 2008). Where parents could previously rely on public education laws for support, they are placed in a new system in which they may not know the laws or policies that can help their adult children (Van Bourgondien et al., 2014). In facing the challenges of this new system, parents have reported feeling as though they were "back at square one" (Van Bourgondien et al., 2014). Moreover, parents must manage increased demands with limited resources, while the intensity of their effort, time, and involvement rises (Bianco et al., 2009; Cadman et al., 2012).

With specialized services for adults with ASD being quite limited, adults with ASD become increasingly dependent on their families for support (Cadman et al., 2012). And, when available, the services are often not specialized enough to address the child's specific presenting problems. That is, the services may not be geared towards individuals with ASD and fail to consider other co-occurring psychological or physical conditions (Cadman et al., 2012).

There is a particular gap for young adults with ASD without a co-occurring intellectual impairment, who are three times less likely to have daytime activities after high school than those who have ASD with an intellectual impairment (Taylor & Seltzer, 2011). The current state of services for individuals with ASD, both with and without co-occurring intellectual impairments, is woefully lacking. The end of high school has been associated with an increase in difficult behaviors in individuals with intellectual disabilities (Taylor & Seltzer, 2010; Esbensen et al., 2008). This is not surprising as these youth go from receiving consistent services to nothing as they wait to access services for adults. Further, given the particularities of ASD, such as strict adherence to routine and an intolerance to change, it is unsurprising that we see an increase in the child's behavioral difficulties during a period fraught with change and uncertainty (Blacher, 2001; Shea & Mesibov, 2005). Even more alarming is the "stalling" or regression in skills that is observed following the graduation from high school. Students with ASD who were found to be experiencing significant improvements while in school, demonstrate little to no signs of improvement on any skills post high school (Taylor & Seltzer, 2010). This can be attributed to difficulties in finding and obtaining appropriate services or settings for young adults with ASD to use and practice their skills after leaving the educational system (Taylor & Seltzer, 2010). As a result of these negative transition outcomes, the caregiving impact becomes heavier as parents must continue to support and advocate for their children (Smith et al., 2010). Further, about 80% of adult children with ASD continue to live with their parents following high school (Shattuck et al., 2011).

Choosing appropriate and specifically tailored goals are important during the transition. Postsecondary goals should be developed with the child and their family and target the skills the child will need in present and future environments (Iovannone et al., 2003). A central goal during the transition from high school to adulthood is to equip students with the necessary skills for employment (e.g., Individuals with Disabilities Education Act, 2004; see 34 C.F.R. §300). Clear objectives provide a clear metric for measuring whether the goal of equipping these individuals has been met. It has been demonstrated that many individuals leave school without having acquired the necessary skills to prepare them for postsecondary education or for employment (Carter et al., 2012; Shattuck et al., 2012). In fact, individuals with developmental disabilities have lower rates of employment than any other group in Canada (Till et al., 2015). Further, they experience more job losses and underachievement in education (Howlin et al., 2004). Additional barriers such as employers' knowledge, capacity and attitudes towards hiring individuals with disabilities, later access to vocational training, and stigma impact their ability to obtain employment (Khayat-zadeh-Mahani et al., 2019).

Professionals working with adolescents with ASD also lack the necessary skills and experience to help with successful transition planning. Transition instruction requires professionals to have a variety of intervention strategies that can be altered to meet the individual needs and strengths of each person (Iovannone et al., 2003). Greater awareness and knowledge about ASD are needed to ensure that interventions meet the multiple needs of these transitioning adolescents (Kurcharczyk et al., 2015). Professional development is hindered by several barriers including limited time, competing work demands, and buy-in from the professionals (Kurcharczyk et al., 2015). Although knowledge dissemination on effective interventions for youth with ASD has improved, there is still a gap between knowledge and application (Greenwood & Abbott, 2001).

It is evident that the transition to adulthood can be difficult for most families. Successful transition outcomes have been linked to parental involvement, however, parents report few opportunities to participate in their child's transition planning (Hagner et al., 2012; Kurcharczyk et al., 2015). Parents who were involved in their child's transition planning felt more empowered and positive about their child's experience (Neece, 2009). Further, these parents reported higher well-being than parents who were dissatisfied with their child's transition (Neece, 2009). This underscores the role that successful transitions can have on the overall ecology of the family (Bronfenbrenner, 1977; Neece, 2009).

Summary

The previous information demonstrates that parents of children with ASD are chronically stressed. These stressors arise from the behavioral challenges, financial strain, and difficulties obtaining services for their child. Transitional periods exacerbate these difficulties. The diagnostic period is the parents' first step into social services. During this transition, parents are simultaneously trying to access services to obtain answers about their concerns about their child's development while processing their own fear and grief at the thought of their child receiving a diagnosis. When children graduate from high school, the transition from adolescence to adulthood leads to increased stress due to a lack of age-appropriate services, obstacles in obtaining services, and the increase in children's difficult behaviors that occur during this period. The present dissertation will qualitatively examine the perceptions of parents' experiences accessing and using services during these transitions.

Present Study

There is a rich literature demonstrating that parents of children with ASD experience greater parenting stress as compared to parents of children with other disabilities and parents of typically developing children. However, less is known about parents' experiences with service access and care, especially during transitions in adolescence. This transition is significant as it is associated with a drop in services due to fewer resources for adolescents and adults with ASD (e.g., Taylor & Seltzer, 2010). Learning more about parents' experiences could provide salient information about how service access and policies might be altered to reduce parenting stress in this population. A qualitative exploration of their experiences would gather rich information and allow the participants to share their own stories in a deeper, more meaningful way. Understanding parents' experiences can also elucidate the professional practices that increase or decrease parenting stress. Further, it may provide insight as to why families who receive services still report high levels of distress.

With these goals in mind, the current dissertation consists of two studies. In Study 1, mothers who had adolescent children formally diagnosed with an ASD were invited to share their experiences with accessing and using specialized services during transitions in adolescence. The specific transitions targeted were the transitions to high school or from high school to adulthood. Using a constructivist grounded theory approach, the purpose of the study was to: (1) explore parents' perceptions on the quality of the services, including communication and collaboration with professionals, (2) examine the practices that helped or hindered their well-being, and (3) explain the ways in which policies could be created or adapted to be more helpful to them and their families.

In Study 2, the authors used the coding scheme that emerged from the data in the first study to examine interviews that were conducted with parents of younger children with ASD for similar themes. These included mothers and fathers of children between the ages of 3 and 11 years old. The goal was to explore if similar themes would be present when asking this population about their experience with service use and access. This process served to validate the themes and the theory that were created from Study 1 and to extend its implications across the childhood period.

Methodological Framework

Grounded Theory (GT) is one of the most widely used approaches in qualitative research (Padgett, 2016). Classical GT emerged in the 1960's (Glaser & Strauss, 1967). GT is an inductive approach that sets out to discover and/or construct a theory to reflect the experiences of the population of study (Sebastian, 2019). This approach describes systematic yet flexible guidelines for gathering and analyzing data (Charmaz, 2014). It attempts to bridge the gap between theory and research (Olshanksy, 2014). In lieu of grand theories, GT favors small theories that allow for more authenticity and "groundedness" of the experience being studied (Padgett, 2016).

Since the creation of Classical GT, different types of GT have emerged (Padgett, 2016). Constructivist Grounded Theory was derived from Classical GT and differs from it in several aspects. These aspects include the literature review, the creation of research questions, the role of the researcher, as well as data analysis and theory generation (Charmaz, 2014; Sebastian, 2019; Thornberg & Dunne, 2019).

In most studies, the literature review is conducted prior to beginning a study to obtain information about the topic of research and to help guide the creation of appropriate research

questions. In Classical GT, the literature review is only conducted after the data have been analyzed (Thornberg & Dunne, 2019). This approach argues that the researcher should be neutral and “discover” the theory inherent within the data without bias from previous literature (Thornberg & Dunne, 2019). Similarly, research questions are not established prior to data analysis (Sebastian, 2019). In Classical GT, the research questions become clearer as one conducts data analysis (Sebastian, 2019). Constructivist GT refutes the claim that researchers can be completely unbiased. It acknowledges that preconceptions exist and uses existing literature to help create pertinent research questions (Sebastian, 2019). Further, it argues that prior knowledge can strengthen a research project as long as it does not define it (Sebastian, 2019). This approach views prior knowledge as a “tool” that opens inquiry as opposed to shutting it down (Charmaz, 2014).

The stance in Classical GT is that the researcher should remain distant and detached from the data (Sebastian, 2019). The researcher must be a neutral observer whose main objective is to report the theory that arose from data, with no outside bias from the researcher (Sebastian, 2019). This is a sharp contrast from Constructivist GT that argues that the researcher has an active and essential role in the process (Sebastian, 2019). This approach denies the notion of a neutral observer and instead, acknowledges the subjectivity and the researcher’s involvement in the interpretation of the data and construction of the theory derived from it (Charmaz, 2014). This approach refutes that data or theory is “discovered”, but rather posits that they are constructed as a result of the researcher’s interactions with the participants and the data (Charmaz, 2014; Sebastian, 2019).

Grounded theory provides a framework for qualitative investigation and guiding principles for conducting research (Charmaz, 2014). The coding process in Classical GT includes two phases of coding (substantive and theoretical coding) in which the researcher identifies patterns within the data (Sebastian, 2019). During the substantive process, the constant comparative method is used whereby data are being compared against one another to identify similarities and differences and create central themes (Charmaz, 2014; Sebastian, 2019). The substantive coding phase helps researchers to identify the main phenomenon. This approach argues that there should only be one phenomenon to which all the other categories are then connected (Sebastian, 2019). This, in turn, leads the researcher to begin creating a substantive theory. In Classical GT, the end goal is the creation of a formal theory (Sebastian, 2019). The theory constructed is based solely on the data and unaffected by the researcher’s biases (Sebastian, 2019). Constructivist GT methodology also occurs in two phases. In the first phase, the researcher codes all the data, identifying one or several core themes (Charmaz, 2014). Unlike Classical GT, Constructivist GT allows for more than one core theme or phenomenon (Charmaz, 2014). Further, this approach allows for more flexible coding guidelines, allowing the researcher the freedom to code in different ways (e.g., word-by-word, line-by-line; Charmaz, 2014). In the second phase of coding, the most used codes are identified, and remaining data is organized within those codes (Charmaz, 2014). The theories constructed in Constructivist GT are interpretations of the phenomenon, based on the interactions between the researcher, the participants and the data. This approach argues that the theory is dependent on the researcher’s view and cannot exist without it (Charmaz, 2014).

Constructivist GT was deemed to be the best methodological approach for Study 1. There are several arguments that help support that this approach was the best fit. Specifically, the strengths of Constructivist GT methodology include honouring the voices of its participants, taking into consideration the context, and recognizing the role of the researcher in the

interpretation and generation of theory (Charmaz, 2014). Study 1 involved learning about the experiences of mothers with service access during transitions in adolescents. A central goal in GT is to explain a process or action, and it is typically used to study life transitions (Charmaz, 2014). The dynamism inherent in GT comes from interviews with individuals undergoing (or having undergone) a significant transition or life change (Padgett, 2016; Sebastian, 2019). As such, GT theory differs from other qualitative studies that adopt more of a “freeze frame” picture of a phenomenon (Padgett, 2016). It studies the process of the individual undergoing the transition. The types of transitions can vary greatly from the common (e.g., starting university) to less common (e.g., winning the lottery; Padgett, 2016). As such, this approach allowed for the clearest picture of the experiences of mothers as their children transition to or from high school. Further, Constructivist GT argues for purposeful sampling of participants. That is, the researcher selects participants who can provide information about the phenomenon being studied (Charmaz, 2014).

The data set for Study 1 came from a larger project examining the impact of parenting stress on physical and emotional well-being for parents of children with ASD. Study 1 had a large sample of participants ($n=78$). Grounded theory studies usually have moderate sample sizes (e.g., 20 to 30 participants), though smaller or larger samples are also appropriate (Padgett, 2016). Consistent with the Constructivist GT view of a literature review, the questions for the interview were derived from a review of the research literature on parenting stress for parents of children with ASD (Charmaz, 2014). The interview questions were created to gather information on specific stressors (e.g., waitlists, obtaining referrals, interactions with professionals) and to seek the participants’ lived experiences with these stressors. Finally, the systematic yet flexible data analysis guidelines outlined in Constructivist GT allowed the researcher more freedom when analyzing the data. For example, Constructivist GT allows for the possibility of more than one core category (Charmaz, 2014). Given the numerous parent stressors identified in the existing research literature, it is possible that more than one core category might emerge from the data and thus a better methodological fit. Further, Constructivist GT posits that the researcher’s interpretation is a key component in theory creation (Charmaz, 2014; Sebastian, 2019). This allowed the researcher to provide a more in-depth theory that includes not only the parents’ lived experiences, but connections to existing research to explain current gaps in the literature.

Method

Design

Study 1

Ethical approval was obtained for Study 1. The interview data analyzed in the current study were drawn from a much larger primarily quantitative project which investigated the emotional and physical well-being of mothers of adolescents with ASD. The phases of the current study are outlined in Figure 1. The participants completed the following tasks following their screening and acceptance into the study.

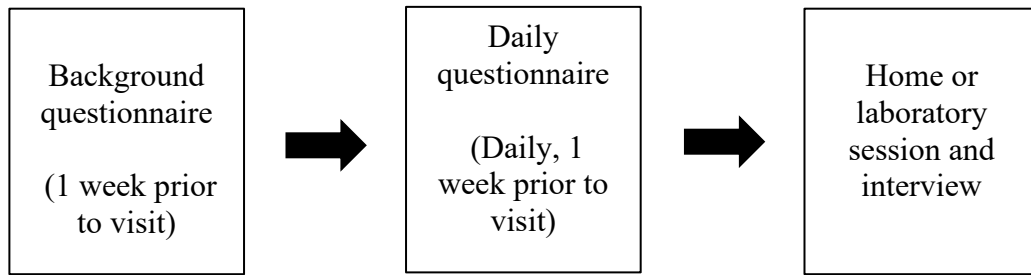


Figure 1. Study 1 design

The study lasted approximately 3-4 weeks from the time the participant was recruited to the completion of the study. Participants completed several tasks prior to the visit, some of which are outside of the context of the current study. Prior to the study interview, participants completed a background questionnaire that collected demographic information, relationship functioning, the presence of depressive or anxiety symptoms, and information about the child (e.g., diagnosis, functioning, presence of behavioral problems). Mothers simultaneously completed a daily diary record for a week prior to the visit. This assessed mothers' perceptions of their daily stress, their child's emotional functioning, worries, and the coping skills used during that day. In addition, other tests that provided information about their physiological well-being (e.g., saliva samples, blood test) were done prior to or during the visit.

The visits took place in a quiet room at the university or in the family home, based on the mother's preference. Visits were conducted by a phlebotomist and a research assistant. During the visit, physiological tests were conducted (e.g., blood draw, height, weight, and blood pressure measurements, and their saliva samples) by the phlebotomist. The participants completed a health questionnaire with the research assistant and participated in two computerized tasks: the PASAT and the Go/No Go task. The research assistant also conducted the Mini International Neuropsychiatric Interview (M.I.N.I.) and the Transition Interview with the participants at the end of the visit. For the purposes of this study, the information collected from the Transition Interview was used for qualitative data analysis.

Study 2

Ethical approval was obtained for Study 2. The interviews for Study 2 also came from a larger study investigating the impact of stress on emotional and physical well-being of parents of children with ASD. This study had a similar design to Study 1.

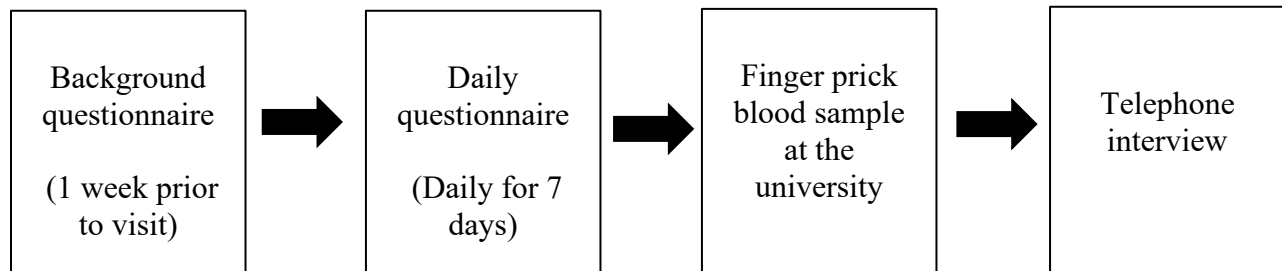


Figure 2. Study 2 design.

The study lasted approximately 2-3 weeks from the time the participant was recruited to the completion of the study. Participants completed a similar background questionnaire to Study 1. Differences between the interviews included not having a component asking about their child's transition and service providers. Parents completed the same daily diary record for a

week prior to the visit that assessed mothers' perceptions of their daily stress, their child's emotional functioning, worries, and the coping skills used during that day. Participants were asked to come to the university laboratory on the last day of their daily diary for a blood sample via finger prick. Then, participants were scheduled for a phone call with a trained research assistant. During the phone call, the research assistants conducted a semi-structured interview in which parents were asked to describe their daily stressors, their experiences as parents of a child with ASD, and their experiences with accessing and using services for their child. These interviews were used for qualitative data analysis in the present dissertation.

Participants

Convenience, yet purposeful, sampling was used for both studies. Parents were recruited through social service centers that offer services for individuals with ASD and through media advertisements (e.g., advertisements in newspapers, online sources, university boards). The researchers met with professionals from the social service organizations to explain the eligibility criteria for the study and provided flyers containing contact information for distribution. The research coordinator screened and scheduled interested participants.

Study 1

The participants for Study 1 were mothers of children with adolescents with a primary diagnosis of ASD. That is, the child could also have had co-occurring conditions (e.g., Attention Deficit Disorder of either type, anxiety, epilepsy) but must also have had a formal diagnosis of ASD. Exclusion criteria for the study were if their child was not between the ages of 12 and 22; was not currently in school or one-year post-graduation; was not living at home at least 50% of the time; did not have a diagnosis of ASD; the mother had an autoimmune condition or was on medication that altered immune functioning; the mother could not read or speak in English or French; and did not live within 60 km of Montreal.

The final sample consisted of seventy-eight mothers ($n = 78$) from Montreal and surrounding rural areas. The interviews used for the present study were from the first time point of the first cohort of participants from the larger study. Of the 78 participants, 41 were French speaking and the remaining 37 were English speaking. The children ranged in age from 12 to 22. There were 64 males and 14 females. In our sample, 31% the children with ASD were between the ages of 12 and 14; 42% between the ages of 15-17; 26% between the ages of 18-20; and 1% were 21 or 22 years old.

Study 2

The participants for Study 2 were parents of children with a primary diagnosis of ASD. This study did not exclude fathers. Exclusionary criteria for the study were the child not having a primary diagnosis of ASD; if the parents smoked; if the parent had an autoimmune condition or was on medication that altered immune functioning; the parent could not read or speak English or French; and the parent was not able to come to the lab for the finger prick.

The final sample consisted of twenty parents ($n = 20$) from Montreal and surrounding areas. Of the 20 participants, 9 were French speaking and the remaining 11 were English speaking. Three of the participants were male and 17 were women. The children ranged in age from 3 to 11. In this sample, 25% of the children were between the ages of 3 and 5; 30% were between the ages of 6 and 8; and 45% were between the ages of 9 and 11.

Data Collection

Study 1

Participants were interviewed in their home or at the university, depending on their preference. The interviews were conducted in English or French based on the mothers' preferred language. The interviews varied in length and were between 20 to 60 minutes. The interview was recorded through a recording application on a laptop. Trained research assistants administered the Transition Interview (TI). The TI was created by the researchers and consists of four open-ended questions that gathered information about the participants' experiences with service access and quality of service (refer to Appendix A the TI). Questions included, "When working with the professionals involved in your child's care, what practices did you find helpful and/or unhelpful?" and "If you could make any changes to your child's transition programming or the transition outcome (if youth has transitioned into adult services), what would it be?". These questions were created by the researcher by reviewing existing literature on the difficulties with service access for families of children with ASD. The questions were kept broad to allow the participants the opportunity to share their own experiences without being influenced by the researcher. Probes were used to seek clarification and more in-depth information about the participants' experience.

Two trained research assistants transcribed the interviews verbatim. The author of this dissertation reviewed the transcripts with the recordings to ensure that the interviews were transcribed correctly. The research assistants were told they could omit certain pieces of text in which the participant repeated or used words/sounds as they were thinking (e.g., "um..um..well...um..." and "oh..oh...oh!"). Given that the goal of the study was to describe the essence of their experiences, these were not necessary for coding the data.

Study 2

The measure used for Study 2 was the Stress and Service Interview (SSI), a semi-structured interview created by the researchers that explored parents' experiences with daily stressors and service access. The SSI was part of a larger interview that also included an Expressed Emotion exercise in which the parent was asked to speak about their child for five minutes without interruption from the interviewer. This portion was not analyzed for the purposes of the present dissertation. The SSI consists of seven open-ended questions that gathered information about the participants' daily stressors, whether these stressors changed over time, the experience of being a parent of a child with ASD, and their experience with service access and use (refer to Appendix B). The interviews were conducted in French or English, depending on the parent's preference. Two trained research assistants transcribed the interviews verbatim. The author of the dissertation reviewed the transcripts with the recordings to ensure that the interviews were transcribed correctly.

Data Analysis

Study 1

Consistent with the Constructivist Grounded Theory (CGT) methodology outlined by Charmaz (2014), the author kept a journal with memos during the data analysis process. The constant comparative method was used. With this method, all data is in constant comparison with all other data to identify differences and similarities (Chamaz, 2014; Chun Tie et al., 2019). This method begins with the first round of coding and continues until the theory has developed. Initial codes are compared to other codes and eventually, codes are collapsed into meaningful

categories (Charmaz, 2014). The constant comparative analysis generates theories through an inductive process (Chun Tie et al., 2019).

In Study 1, the author and two trained research assistants conducted several readings of the transcribed interviews. In the initial phase of coding, they conducted line-by-line coding of twenty-five transcripts to identify initial codes. Codes were kept close to the data. Data segments were compared with previous data segments and codes to determine if the data segment could fit in a previous code, as per the constant comparative method. Each person took notes of grand themes that were emerging in the data. The themes were then discussed as a group. The group selected segments that were relevant for answering the research questions and compared, combined, or modified the codes. This process grouped the codes into categories that were related or applied to the same process. The coders then discussed the emerging categories to ensure that they all agreed with the codes and their subsequent categorization. If there was a disagreement regarding the coding or categorization between the coders, this was discussed and explored until a consensus was reached.

In the next phase of focused coding, line-by-line coding was conducted for the remainder of the transcripts to look for more focused codes. This process entailed coding what was relevant for the research questions, selectively coding around emerging categories, and clarifying the meaning of the categories. Further, theoretical sampling was conducted. The coders examined new interviews to see if there was further evidence of an emergent theory. In this process, the coders select the codes that are most significant to help with the conceptualization of the theory. The researchers met to discuss the phenomenon. The final coding scheme developed from this process resulted in a three-tier categorization scheme (refer to Appendix C).

In the present study, credibility and trustworthiness were established in several ways including data saturation, identification of researcher bias, and the incorporation of member checking (Charmaz, 2014). Data saturation occurs when no new data emerges in the sample (Charmaz, 2014). Given the sample size of the study, as well as the specific phenomenon being studied, data saturation was achieved early on.

As an additional measure of credibility, interrater reliability was conducted with a new research assistant who was blind to the purpose of the study. That is, he knew the overall goal of the larger study but not of this specific project. Twenty transcripts (roughly 25% of the sample) were randomly selected for interrater reliability. The author and the research assistant coded the transcripts separately. Once completed, codes were entered into an Excel file to note the number of codes on which they agreed or disagreed. Kappa's coefficient (K) was then used to calculate interrater reliability. Kappa was selected as it is a robust statistical measure of interrater reliability used in qualitative research (McHugh, 2012). Kappa's co-efficient was calculated at all three levels of the coding scheme. A higher Kappa indicates stronger agreement between raters. Interpretations of level of agreement for Kappa's co-efficient have been broken down as follows: 0-.20: None; .21-.39: Minimal; .40-.59: Weak; .60-.79: Moderate; .80-.90: Strong; Above .90: Almost perfect (McHugh, 2012). The results for each of the three levels can be found in Table 1.

Table 1
Kappa's Coefficients for Each Coding Tier

Tier Level	K	Level of Agreement
1	.84	Strong
2	.86	Strong

3

.87

Strong

Study 2

For the Study 2, the author used the coding scheme developed in Study 1 and applied it to a set of transcribed interviews from parents of a younger age group. The author and a researcher assistant used line-by-line coding in this initial phase to identify the main themes emerging from the data. Memoing (writing reflective notes about the data) was used to identify any new themes that had not emerged in Study 1 (Charmaz, 2014). The author and research assistant met to discuss the initial codes and any new emergent codes. Emergent codes were discussed to see if they could be classified into existing categories. In the case of a disagreement regarding coding, the meanings of the codes and the context were explored and discussed until consensus was reached. Any codes from Study 1 that were not observed in Study 2 were removed from the coding scheme. As such, a new coding scheme was developed for this sample (refer to Appendix D).

Results**Study 1**

The author set out to explore the experiences of mothers with service access and service use during their child's transition in adolescence. The findings demonstrated rich detailed accounts of the participants' experiences and the presence of consistent themes. While there was some variability in their experiences (e.g., some stressors were more present for some than others), four core categories were evident across the mothers in this study: Parent Stressors, Services, Professionals, and Solutions. As can be seen in Figure 3, the category, Parent Stressors accounted for a large percentage of the codes in the study, followed by Professionals. The categories Services and Solutions, while important, made up fewer of the codes in the study. Each of these are explained in greater detail in the following sections.

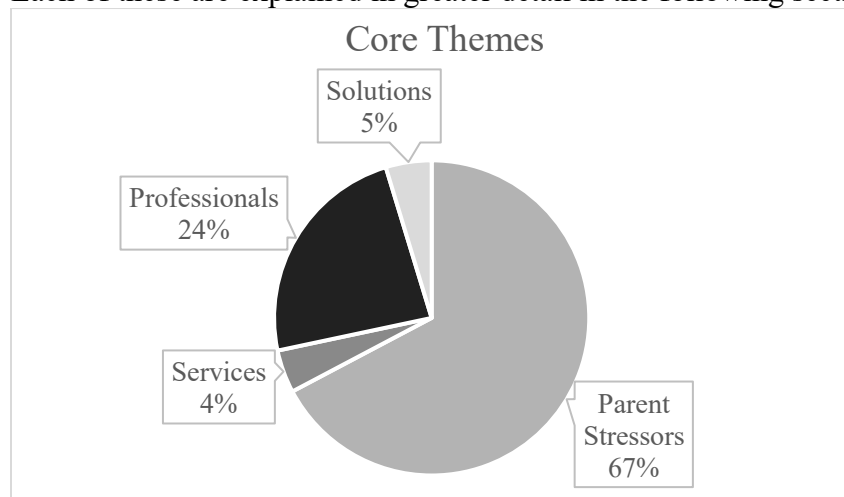


Figure 3. Core themes in Study 1.

Parent Stressors

Codes in this category reflect the aspects that were cited as significant stressors for mothers, and one category which identified practices that alleviated stress. This main category consisted of eight sub-categories: Unmet Needs; Child-Related Stressors; Daily Hassles;

Emotional Stressors; Service-Related Stressors; Emotional Reactions; Extra Roles; and Buffers of Stress. The sub-categories and the tier-level codes for Parent Stressors are listed in Table 2.

Table 2

Sub-categories under Parent Stressors in Study 1

Core Category	Sub-Categories	Tier-Level Codes
Parent Stressor	a. Service-Related Stressors	i. Staff turnover
		ii. Turning to private services
		iii. Lack of services for adolescents/adults
		iv. Fighting for services/Advocacy
		v. Paperwork
		vi. Waitlists
		vii. Obstacles
		viii. Timing of services
		ix. Appropriateness of services
		x. Continuity of services
		xi. No emergency services/placements
	b. Unmet Needs	i. Services for child/family
		ii. Access to information
	c. Child-Related Stressors	i. Behavior problems
		ii. Communication
		iii. Child's well-being
		iv. Relationship child
		v. Health-related issues
		vi. Co-occurring conditions
	d. Daily Hassles	i. Transportation for child
		ii. Home-related stressors
		iii. Financial
		iv. Employment
		v. Family schedule/organization
	e. Emotional Stressors	i. Concerns about child's present/future
		ii. Parent aging
		iii. Social isolation
		iv. Marital problems
		v. Mourning child's disability
		vi. Judgement of others
	f. Emotional Reactions	i. Anger
		ii. Guilt
		iii. Sadness
		iv. Feeling invalidated
		v. Frustration
		vi. Happiness
		vii. Anxiety/worry
	g. Extra Roles	i. Supplemental services provider

- | | | |
|----------------------|------|-----------------------------|
| | ii. | Care coordinator |
| | iii. | Advocate |
| h. Buffers of Stress | i. | Other parents/professionals |
-

Service-Related Stressors. These stressors were the most cited across mothers. Waitlists were a significant source of frustration. Mothers reported long wait times across all types of services that ranged from a few months to a few years. Wait times for placements for their adult child was several years with some mothers reporting at least a 10-year wait. Mothers described the current system as being “reactive” as opposed to “proactive” with emergencies or crises leading to the start of services. One mother stated that, “everything is done in a crisis”. Mothers shared situations in which their adolescents hurt themselves or someone else that resulted in rapid access to services. These situations created significant distress for mothers who not only feared for the well-being of their child, but also worried that their child would be labelled or stigmatized as a result of their behavior.

Other mothers reported having been informed that the only way to access services quickly is to demonstrate that they are at their “breaking point”. Mothers reported having to threaten to leave their children in hospital emergency rooms or with child protective services so they would be taken seriously. One mother shared the advice that she had received from a professional that worked in the social service system.

[The waitlists! Just waiting and waiting, all the time. 5 years to receive CRDI (Centre de réadaptation en déficience intellectuelle) services. I had to threaten to leave my child with the Department of Youth Protection to finally receive services because someone who works in the system told me that’s the only way they would hear me and do something.]

Many mothers reported turning to private services for their child. There were several reasons for this. Most often, mothers sought private services because the waitlists for the same service in the public sector was too long. Mothers worried about their child’s development being compromised and did not want to experience “stalled” development. Other mothers reported that they did not want to deal with the “hassle” of the public system where waitlists were long, and applications involved insurmountable amounts of paperwork. One mother shared her experience in applying for tertiary care services for her 13-year-old son.

[I spent an entire afternoon sitting with seven people when he was being transferred to the CRDI. Filling out forms, answering a million questions, it was such a big hoop. And the worst part, is that I did all of this for next to no services and services that are not useful. So yeah, we are sticking with private services. It’s less of a circus.]

At times, mothers preferred to seek out private services as they believed that these professionals were better trained than professionals in the public system. Mothers reported that professionals in the public sector often lacked knowledge about ASD and did not have a lot of experience working with that population. This belief appeared to be especially prominent when mothers spoke of professionals in the public school system.

[It's very difficult to have services anywhere. The waitlists are insane and there are no services anywhere. The school system is worse because a lot of the people there don't have the experience of knowledge to work with these kids so you know, I have to send him to a private school because otherwise he wouldn't get what he needs.]

Mothers were frequent advocates for their children. They reported continually fighting with service providers to ensure that their children were receiving the care they needed. Mothers called supervisors, managers, and heads of organizations in an attempt to "get things moving". One mother reported speaking with politicians to develop more services for adults with ASD.

[I have attended one seminar after another on how to figure out, and I've written one letter after another to every MP, mayor, you name it, trying to get the ball rolling, to get them to create what is desperately needed in terms of group housing. I am willing to do it. I wish there were more cohesive, adult support services available.]

Services for adolescents and adults were found to be woefully lacking. One mother described the situation as leaving the adolescents "high and dry". Mothers reported a lack of appropriate programming that emphasized the necessary skills to help their children transition to adulthood. With the arrival of puberty and emerging issues around sexuality, mothers reported feeling lost as to how to help best support their growing children. A mother reported that the situation was similar to everything else related to ASD stating, "It's the lack of programming. Like the rest of it, we (parents of children with ASD) have to pick up the slack." While some mothers expressed frustration and anger at the lack of services for adolescents, others expressed tired resignation.

[They (service providers) will give the minimum. That's what we can expect, the bare minimum. They (child with ASD) won't die of hunger, they will get welfare, and when I die, they will find him a place to stay, regardless of whether he will be well or not or if he will like the people he is with. It's not how I want to do it, but it's how it is.]

Obstacles such as cost of services, the location and time of services, and criterion-based services were all reported by mothers. Mothers appeared to find criterion-based services to be the most frustrating. Adolescents and adults would not be able to receive services due to their age, diagnosis, level of functioning, or language. One mother expressed frustration that her son never seemed to "fit the box" and was often excluded from services due to these conditions. Another stressor was the amount of paperwork that had to be completed with every new service. Moreover, every few years, mothers would have to get paperwork completed by various professionals to "prove to the government" that their child still had a diagnosis of ASD so they could continue to receive funding and receive tax breaks.

[The government makes us fill out all this paperwork for funding and it costs me \$150 for the doctor to fill out his section. And you know, autism is not a cold...it's not going to disappear next week. But we still have to fill out this paperwork every two years. It's frustrating.]

High staff turnover and lack of continuity were sources of anger and frustration. Mothers reported having a “revolving door” of professionals. With each new worker, mothers would have to start over. Further, they worried about their child’s ability to form a bond and work with a professional, given the social and relational difficulties associated with ASD. Moreover, certain professionals would require parents to complete new questionnaires and other types of paperwork. Some mothers reporting a new worker every few months, resulting in “starting over” 3-4 times a year.

[She is coming for two months. Everybody in the CLSC, everyone is hired for 2 months, 3 months, a monthly basis, but it just doesn’t work. For parents like me, I had to tell my whole life story everything. Every 2 months, I’m wasting my time. At one point, I stopped doing it. When they would ask for meetings, I would say I’m too busy because it’s worthless.]

Mothers reported rarely having access to emergency services such as placements. Several mothers shared that they reached out to professionals for temporary emergency services and were turned away. Some reported that the timing of the services was off in that the service was not available when requested but offered at a later time when it was no longer necessary. A mother shared an experience where her adolescent son was becoming increasingly aggressive and she feared for her safety.

[They (professionals) call to check in and ask how things are going. They asked if he was a danger to himself or others. The last time they called, I said yes, he’s starting to get stronger and he’s starting to throw things, and he comes at me fast. He’s 6 ft, 200 lbs, he could do some damage. So yes, he’s becoming a danger, and that’s when we finally got services.]

Not only were services not available when requested, but mothers reported that they often ended prematurely. This appeared to be due to service delivery protocols whereby parents are only allotted a certain number of sessions in a cycle. Once the cycle is complete, they return on the waitlist to await their next cycle. Moreover, it appears that services are available on a priority basis wherein children with the most difficulties get the services, and children who have less “urgent” needs wait for longer periods.

[Because now, they are in an “episode” approach. That means the squeaky wheel gets the grease. The minute things stabilize, they want to close his file at the center. And if a crisis occurs, they tell us they will re-open his file. But he’s a young adolescent, he has so many things to learn to be autonomous! And his behavior...if he hits, they will do something, but the moment he stops, even if it hasn’t been long, the services close.]

Another service-related stressor that emerged was the age of consent. In Quebec, the age of consent for services is 14. Some mothers were angry that their adolescent was able to decide whether or not he or she wanted services. This was a problem that was frequently cited for mothers of children with higher functioning ASD. Mothers reported that due to oppositional behaviors, adolescents would refuse services “just because they can”, even though they desperately needed the support. Parents are held accountable for their child until the age of 18 or

21. Yet, they are being told they cannot receive services their child needs because their 14-year-old terminated their services.

[I hate this stupid rule about kids being able to give consent at 14. If they don't consent, then they don't get the services but it's a huge impediment, you know? If you have a child who needs to see a psychiatrist, I don't think a 14-year-old has the mental capacity to refuse the service. As the parent, I am legally responsible for that child until the age of 18, so I don't understand why I don't have to right to be able to insist on those services. So, you're stuck in this circle: You can't get help because they don't want it, but then they (professionals) turn around and say you're responsible for your kid because they did X.]

Further, a child's right to refuse services leads to frustration for mothers who report losing access to services that they need as well. Mothers rely on services to help teach them how to best support their child. If their child refuses their services, mothers lose their services as well. The professionals will not remain involved with the family if the child refuses services.

[He can decide now if he wants services because he's older than 14. He can refuse the services, and I can try and convince him to keep them, but I have no control. The problem is I still need services to know how to manage and help him. It's ridiculous.]

Mothers reported similar situations when their child turned 18 and they were unable to attend medical appointments.

[It's been difficult because once he turned 18, they cut out the parent and this is a huge problem because all of a sudden you are taking what he says and what he wants and what he is applying. What he says may not be in his best interest. He is nowhere near ready to make these choices. All I get from them (professionals) is, 'I can't discuss this with you'.]

Many mothers reported that the services often did not meet their needs or the need of the child. They expressed frustration at having persisted and surmounted many obstacles to get the services only to find out that it was not what they expected or needed. Mothers reported professionals being unwilling to work on the goals established by the parent, such as appropriate social and leisure activities for their child. Many mothers felt that services were not individualized and were offered in a rigid, bureaucratic way.

[It's disappointing. They (professionals) are like bureaucrats, they're following some sort of procedure. They have a job and do it in a bureaucratic way. If there is something that is a curve, it's "Oh whoa, that's more work". It's a bit of a farce. But I am happy they participate but I don't get the help I need. If I get overly critical, I know they have the power to shut the case and say it's done. So, I'm 'cheery' and 'happy'.]

Unmet Needs. Unmet needs consisted of a general lack of services and a lack of access to information about services available. Mothers reported unmet needs in the form of unmet needs for a specific service, or inexistent services. A mother of a 19-year-old expressed her

frustration with services not addressing the needs for her son to become travel trained so he can go to his activities independently.

[I am so frustrated at the limited options that are offered after high school. He only has one option because for the other ones, you need to be travel trained, so he's limited to this education. They only work on life skills, and on nothing else. So, we're working on his reading and math...we're compensating for the lack of services that are out there.]

Access to information about services was lacking. Many mothers reported that they were resourceful and spent hours searching for information. Even with this effort, they had difficulty finding the necessary information as information was not made readily available on websites or pamphlets.

[In the public system, it was horrible accessing information, getting information, and finding up to date information. If I wasn't the type of person that went searching for stuff, I'd never find anything. And even then, I couldn't find much.]

Mothers relied on social workers and other professionals to provide them with information about the services available to them. While mothers expected social workers to share information, professionals appeared to rely on mothers to tell them what they wanted and needed. This disconnect created frustration as mothers reported not even knowing what services they would need.

[I have had this experience with several social workers. They come to the house and ask me what I'm struggling with and we talk about it. But what I'd want is for them to come and tell me what they can offer me. I'll learn about the services we can get and chose what we want. They have told me to ask for what I want, but sometimes I don't even know where to start, let alone what I want.]

Child-Related Stressors. The most reported child-related stressor were behaviors such as hitting, kicking, pushing, screaming, throwing objects, oppositional behaviors, self-harm, and inattention. These problems were more stressful at this age since their "children" were now fully grown and often bigger than them. As such, they could inflict more damage during a crisis. In addition, children often had co-occurring conditions such as anxiety, Attention Deficit Disorder, and intellectual disabilities that increased the complexity of some of their behavioral difficulties. Children were reported to have significant sleep difficulties as well.

Daily Hassles. Financial difficulties were reported by many mothers. These difficulties were due to mothers' not being able to work as they must take care of their child and due to the costs of private services. Mothers were resourceful in finding ways to secure funds. Mothers reported holding bake sales, raffles, and one mother even organized a telethon. Transportation was another daily hassle for mothers as they often spent a lot of their time driving their children to their various appointments. Further, many mothers experienced frustration with adapted transport services. These services come with many conditions including how far they will go and

how many people can be with the child in the transport. As a result, this rendered the services “useless” for some mothers.

[There can only be one other person with her (in the adapted transport). But if she is in a bad mood, she will freak out and I can’t manage it alone. And it’s not like she can go on her own either. And her therapy is so far, so when I cannot organize childcare for my son, I would need to bring him with me, but he’s not allowed to come because there can only be one person with her.]

Emotional Stressors. Concerns about their child’s present and future were prominent for all mothers. Mothers were worried about what their child’s future looked like. Many of them reported feeling worried about what would happen to their child when they are no longer about to care for them. One mother shared an experience where she was unable to find temporary emergency placement for her son. This caused her to wonder, “Who’s going to find a placement for him when I’m not there to take care of it?” Experience within the social service system has confirmed mothers’ fears that there are few services to help their children.

[The problem is when they hit 21. You think it’s easier because you know more, but there is less help for them, there is a lack of socialization, and the isolations gets bigger. That’s what I’m realizing and it’s what is scaring me the most.]

Mothers reported being overwhelmed by fear when thinking about their child’s future and who will take care of them if they pass away. Many reported not wanting to think about it as they were unable to manage the feelings that arose. One mother shared that she had to stop herself from thinking about it as she realized that she had no control over the situation.

[When you think about the future, you start to freak out. So, you can’t think about it. You have to look at things one step at a time and process them. But at night, it all comes back and I start to wonder what will happen when I am no longer there. It doesn’t change anything to think about it, but you try and look into the future. It’s scary, we have no control over that.]

Mothers reported feeling judged by others, from strangers in a grocery store to the professionals working with them and their children. Mothers reported receiving unsolicited advice from others and being viewed as a “bad” parent because of their child’s behavioral difficulties. Fear of judgement from others lead to increased isolation for mothers and their children. Judgement from professionals was found to be especially hurtful. Several mothers reported feeling judged by professionals. A mother of a 13-year-old shared an incident where professionals blamed her for her child’s behavioral difficulties.

[The child psychiatrist told me that the reason my child had problems was because of our ‘symbiotic relationship’, she said that that was the reason he had tantrums. And all this to be told years later that I had a good relationship with my son and that it was what helped him. For five years, I blamed myself non-stop. For what? A judgement made by an incompetent professional. The judgement of professionals...that’s what really hurts.]

A similar situation was experienced by another mother whereby she felt her child's educator was judging her of not having done enough for her child.

[The last educator, the first interview I had was, 'Why didn't you do this, why didn't you do that?'. We go through a lot as parents and we are the ones on the forefront. We only leave the child for an hour a week at the most. Making you feel inadequate, it's the worst.]

Emotional Reactions. Mothers consistently felt frustrated and worried over the course of the interviews. Frustrations arose from a lack of services; inappropriate services (e.g., one that does not address needs); negative interactions with service care providers, including poor communication and feeling judged by professionals; feeling alone and invalidated; and the child's behavioral difficulties. Mothers carried a significant caregiving impact, which lead to feeling frustrated and exhausted. They loved their child but wanted a break from all the parenting they were still required to do, despite their child being a young adult.

[I'd like to get her to a place where I can continue on with my life. I always want to be her mom, but I don't want to have to be parenting every step of her life.]

Further, mothers experienced frustration with problems being present throughout the child's life. Mothers stated that that, during adolescents and adulthood, it was especially salient that certain difficulties would always be present, and that parental support and supervision would be required. They felt isolated and that others in their life are unable to understand their realities.

[I really find it's the 10 year burn out...it's the one thing I struggled with the most and it's really hard to explain to other people. I think that you are isolated more than anything else. He's not as little and cute anymore, so it's harder to explain (his behaviors), 'Guy's picking his nose again'. People judge and it makes you sort of not want to go out.]

Concerns about their child's future, their ability to fit in, and their quality of life were significant worries for parents. Mothers worried about being able to find the right services to help their child progress. They feared they would not find services that would help find independent or support living opportunities for their child. Social isolation was also a concern with mothers reporting that their children would happily play video games all day if they could. Mothers expressed worry that services would not be present to help their children engage in other leisure activities that involved socializing with others. One mother expressed concern at how hard it was for her child to have ASD. She described him as being rather socially aware of his difficulties in relating to his peers, but of not knowing how to improve his situation.

[It's hard to be someone who likes green when everyone else likes red. Either you pretend to like what they like, which is hard because you're not going to have any fun, or you stay on your own. I tell him, I know you like different things, but you have to fake it.]

Extra Roles. In addition to parenting, mothers took on additional roles including advocate, educator, and care coordinator. Mothers often advocated on behalf of their children to get them the services they need. Further, they acted as care coordinators. In this role, mothers find professionals or services (from private or public sector), coordinate services, and liaise with all of the professionals working with their child.

As educators, mothers either supplemented or made up for a lack of services. Mothers reported teaching their children life skills (e.g., cooking), emotion regulation skills, and academics. A frequently reported source of frustrations was that their children were not receiving enough instruction in academics. As a result, mothers took it upon themselves to teach them.

[I know that with her, she needs constant repetition. They do so little in the classroom on math, so I do it with her at home. I do worksheets and find other ways to get her to practice, and eventually she gets it. It just takes a lot of time and repetition.]

Buffers of Stress. Parents of other children with ASD were found to be a significant source of support for mothers. One mother reported that she received the more information from other parents than professionals.

[Parents with children a bit older than mine, they are a great resource for me because they can say “ok we tried this and it was a disaster and we tried that and it worked, or you know, ‘I heard about this, you should check it out’. That’s always been a huge resource for us.]

Veteran parents not only provided important information about services and intervention strategies, but also offered emotional support and validation. Mothers reported feeling supported as these individuals understand the reality of being a parent to a child with ASD.

[It’s reassuring for me, who is alone, to have people who understand what ASD is because you can have friends, you can have all the friends you want, and they want to be understanding, but they don’t live it, I do. They do what they can, but sometimes I need to know things. It’s easier when you have people that know.]

Though many mothers identified veteran parents as sources of support, many did not endorse services such as support groups. Many mothers reported getting the information “on the fly” such as when parents are waiting for their children after a leisure activity. More formal support groups were less helpful as mothers lack the time, the childcare, and the energy to attend the meetings.

[We know we can participate in things to help connect us and make changes. You know, like parent groups. But we just don’t have the energy for it. I used to do it, but now I’m just too tired. I speak with parents in my child’s class, but we are all so busy and tired to formally meet. We don’t have the strength or the time to invest.]

Services

Codes in this category were related to administrative aspects of service delivery. This core category consists of four sub-categories: Inconsistent Information Transmission; Large

Caseloads of Professionals; Mandate Conflicts Between Services; and Funding. The sub-categories and the tier-level codes can be seen in more detail in Table 3. These codes differ from the “Service-Related Stressors” codes found in the previous section as they deal more with policies and administrative aspects of service delivery. That is, these are aspects that are policies of mandates of the specific organization.

Table 3

Sub-categories under Services in Study 1

Core Category	Sub-Categories	Tier-Level Codes
Services	a. Inconsistent Information Transmission	i. Information not transmitted ii. Information transmitted too late
	b. Funding	i. Lack of adequate funding ii. Poor distribution of funds
	c. Large Caseloads of Professionals	
	d. Mandate Conflicts Between Services	

Inconsistent Information Transmission. The way in which information was delivered to mothers was inconsistent. Information was sometimes shared with parents, whereas other times, it was not communicated at all or was shared too late (e.g., program already started, child was no longer available due to a criteria). Moreover, within the same organization, conflicting information was provided. That is, one professional would give information to the mother, but then a professional from the same agency would offer conflicting information. Mothers generally reported having the impressions that the professionals were not even aware of the services themselves and it appeared to be to a larger problem with administrators.

[They are in complete denial of what goes in in their schools. They are like, ‘well they should be telling you that this and this service is available’, and this is the first I am hearing about it. I’m like, ‘Really, because your teachers aren’t saying that, your principals aren’t saying that, your guidance counsellors aren’t saying that.’ Nobody is pointing it out and nobody is telling the parents.]

Funding. There were three core difficulties reported by mothers with regards to funding: Mothers did not receive enough funding to help cover the costs related to the child (e.g., costs of therapy, materials, leisure activities); the government did not provide sufficient funds for services to be delivered adequately; and that funds were not distributed well within organizations.

Certain funds were reported as being attributed to children for services within the school system. Several mothers expressed frustration that their children were not getting the services they were entitled to.

[These kids are an envelope for them (schools). They receive extra funding for these kids, so they want that money, but they do not spend it on the kids. There are services

that my child is supposed to get with that money, but he doesn't have them. I had to get the Office des Personnes Handicapées involved to get him his services.]

Moreover, the funds were used to help other children, who had difficulties, receive services. Mothers reported situations in which their child did not receive the individualized services they needed as the teacher made the most of the educator in the classroom to help other students with learning difficulties.

Large Caseloads of Professionals. Mothers reported both frustration and empathy with professionals' clinical caseloads. Mothers expressed empathy for professionals who were clearly overworked and working with "too many families", however, they also did not want to be penalized or miss out on the services they needed. In most cases, it was social workers who were reported to have significantly large caseloads, as opposed to other professionals (e.g., teachers, educators). As a result, mothers reported that they had difficulty reaching professionals. Further, when they did manage to reach them, it would take them days to follow-up.

[The social worker is a bit difficult because it is hard to get a hold of him and he never remembers stuff we have talked about or done. I know he has too much, he sees a lot of families, but it's still frustrating because you just want to help your child.]

[They have so many files, so it's like they don't have time for you. It takes them three days before they can return your calls, so right now, I don't have faith in social workers.]

For some mothers, the social workers were so busy that they only had contact with them once a year. Mothers recognized, however, that these issues were related to macrosystem level decisions made by administrators and policy makers that are not "on the front lines" and do not understand the reality of families and professionals.

[Everyone tries to do their best. They are working with constraints, I see that. Overall, the problem is somewhere else, at higher government level.]

Mandate Conflicts Between Services. Mothers expressed experiencing "red tape" when attempting to access certain services. They described a back and forth between two organizations who attempted to identify whose mandate it was to offer service to the child. This was often cited when the adolescent had a co-occurring condition (e.g., Obsessive Compulsive Disorder and ASD; physical disability with ASD). In these instances, mothers reported that their child "fell through the cracks" as neither organization claimed to be the mandated service.

[Running after services that he can't receive because he does not 'fit' in their box. He needs psychological services, but because he's autistic, he cannot receive it at the CSSS even if he needs it. It should be the CRDI offering it, but they don't have it, so, they are like, 'you have to figure it out'.]

Further, mothers were unable to "double up" with organizations, even if the services received from either organization were different (e.g., life skills from one agency and behavior intervention from the other). As such, they would have to close their child's file in one agency to have access to the next. The process of doing so, however, was not smooth and mothers were left

for significant amounts of time without service while they stayed in “limbo” between the two organizations.

[I am stuck between services. I can't get services from this organization unless I close services from this other place. And that's fine, but if I just stopped with place 1, and I'm waiting for services from place 2, what happens if there is an emergency? There is something that will happen for sure, we are not safe around him. When he gets angry, it's over and I am no longer safe. I love my son, but I am not safe around him. And I am trapped in fights between two agencies because of dumb criteria.]

Professionals

Codes in this category reflect the aspects that were related to the professionals working with the child or their family. This core category consists of five sub-categories: Experience, Information, Knowledge; Communication; Motivation; Collaboration; and Proactive Intervention. The sub-categories and the tier-level codes can be seen in more detail in Table 4.

Table 4

Sub-categories under Professionals in Study 1

Core Category	Sub-Categories	Tier-Level Codes
Professionals	a. Experience, Information, Knowledge	i. Lack of experience/expertise
		ii. Appropriate experience/expertise
		iii. Poor knowledge of services
		iv. Adequate knowledge of services
	b. Communication	i. Interpersonal skills
		ii. Providing and sharing information
	c. Collaboration	i. Following-up
		ii. Parental involvement
		iii. Multidisciplinary
		iv. Relationship quality
	d. Proactive Intervention	i. Transition planning

Experience, Information, Knowledge. Most often, mothers reported that the professionals lacked knowledge about ASD and experience working with these children and their families. Though mothers reported that professionals from all sectors lacked experience, these complaints appeared to be more common with regards to school professionals. These deficits were often cited when mothers spoke about ineffective strategies or intervention planning. With regards to intervention planning, lack of experience led to intervention goals that did not meet the needs of the family.

[I asked for help to have him travel trained, but they didn't go anywhere except once. They just looked at maps for six sessions. I said, 'He went out once, this does nothing for him. He needs to go out with somebody and be showed and be taught how to get around.' Like, I couldn't believe it. My biggest concern with him is what happens if something goes wrong, who are the people he can go ask for help. He doesn't know how

to handle the things that come up in life. He needs to be taught that. How did she think that this was enough?]

Ineffective interventions were also cited frequently as a result of lack of knowledge. A common scenario was children being “kicked out” of school for demonstrating difficult behaviors. Mothers reported that this strategy was inefficient as it often reinforced the child’s behaviors as the child did not want to be at school.

[The principal is saying, ‘I don’t care, this kid needs to be kicked out’ even though you know it’s not the best course of action for this situation because it’s almost like a reward. You kick him out, he doesn’t want to be there anyways, you’re rewarding his behaviors, but he doesn’t understand that. You need people who know what they are doing.]

In tandem with lack of experience, professionals were found to have poor knowledge of existing services. As a result, mothers became investigators and spent significant amounts of time doing research and calling organizations. Some mothers shared that they had to educate the professionals on existing services they had found. Further, they relied on informal sources of support for information including other parents of children with special needs as well as acquaintances and friends who work in education or the social service system.

A belief that was expressed quite often was that private services meant more knowledgeable and experienced professionals. Parents reported these professionals were more flexible in their approach and offered person-, or family-centered services. Interestingly, mothers who sought and used private services unanimously reported positive working relationships with those professionals. Mothers felt valued and had more opportunities to be involved.

Communication and Collaboration. All mothers had at least one professional with whom they had a positive relationship. Successful relationships were characterized by open and constant communication; collaboration between the mothers and the professionals; multidisciplinary approaches; and high levels of parental involvement.

[I have never been so appreciative of anyone like I am of (social worker). The system has been so terrible but she’s amazing. She’s been with us for four years. She follows up with the teachers, she finds me services. Whenever she hears of anything new, she calls me.]

The behaviors and traits that were most associated to positive relationships were good interpersonal skills; information sharing; coordination with other professionals; following-up with mothers; validating parents’ unique expertise; and working on commonly chosen goals. Further, in positive relationships, professionals considered parents’ abilities and realities when creating intervention plans objectives. Mothers explained that it was all about having a good “fit”. They stressed that chemistry was an important factor to having a positive relationship.

[(What’s been the most helpful to you in these relationships?) We speak daily, hands-on communication, I don’t feel like I’m another number in the bunch or ‘just a parent’, and I am part of the team.]

[When I need advice or things are not going well, or when we need to work on something with him, I always speak with his teachers. We speak everyday.]

Mothers reported having more positive experiences when they had a “team” surrounding them. They expressed that having a small number of professionals meant having more people to help and allowed the various professionals to intervene at different levels. One parent attributed this team approach as the reason behind her child’s successful transition to high school.

[You really do have to build a team around your special needs child, you do. You are the anchor as the parents, no question. However, the transition went very smoothly because that team was in place.]

Lastly, mothers enjoyed when professionals included them in their child’s therapies to teach them how to work with their child. This also served to help the child generalize his or her skills to other environments.

[What I liked was that after the session, she would call me into the room and show me what they learned in the session. I found it so helpful because she guided me and everything she did, I did at home.]

Negative relationships were characterized by a lack of communication; no follow through or follow-ups; poor collaboration between parents and professionals; and little parent involvement. Behaviors and traits such as poor interpersonal skills, “God complexes”, lack of validation, and lack of common goals were also associated with poor relationship quality. Mothers reported feeling frustrated when professionals asserted themselves as the “experts” and downplayed mothers’ knowledge of their children. One parent reported having an altercation with a professional when she expressed her opinion on an intervention being planned for her 16-year-old daughter.

[She takes it like I am pointing out her weaknesses in her job. I suggested using visuals to help her (daughter) understand, but then she (worker) got mad and said, ‘Do you want to work with me or not? I gave you my clinical opinion.’ It was like I couldn’t say what I thought about it.]

A similar sentiment was echoed by a mother who felt as though she was in competition with her son’s educator.

[I think it’s a personality conflict between the two of us. I take care of him all the time, I know his every need and how he feels. She sees it as a fight. It’s like she looks at me and thinks, ‘I can do better than her’ and that bugs the crap out of me because what he knows, I taught him.]

Mothers cited lack of common goals as a great difficulty. There was a discrepancy between the needs identified by the parent and those identified by the professionals. Most often, this discrepancy was around academics. Professionals proposed interventions around behavior

management and the development of life skills, often at the expense of academics. While mothers acknowledged that these skills are important, they also wanted some academic goals. Some parents reported that they wanted professionals to focus on academics at school as they felt less equipped to teach these skills to their child.

[They don't teach him math but things like how to wash his clothes, how to wash dishes. I spoke with the principal at the end of the year because I have no idea what he is learning in math outside of what I taught him. I have the impression it's basically a babysitting service. I would make a lot of changes because teaching him to cook and clean, I can do all of that at home.]

Parents worried about a regression of academic skills as instruction was focused on other aspects of development.

[I felt like she was going backwards. She is getting less and less academics and they think she's only grade 3-4 level, but I think she's more than that. They use the words like 'plateau' and 'regressing'. I thought to myself, 'My gosh this math, she could have done this years ago and now she has forgotten'. This isn't fair, you aren't teaching these kids and you wonder why I'm upset, because you aren't teaching them. Some of these kids are motivated and want to go somewhere, do something, they have dreams. Her dream is to have her high school leaving diploma and it's not looking like she will at this point. It's a glorified babysitting service.]

Mothers reported that professionals would fail to consider the realities of families. Professionals would create elaborate intervention plans that required too much of the parents' time. Or, the plan would not take into account potential reactions, such as aggressive outbursts, that parents would be dealing with on their own.

[She told me to take away the laptop and I'm like, 'Okay, do I want a meltdown from a 6'1, 200 lbs strong young man absolutely pulling the place apart?' She makes suggestions, but she is not thinking about what the consequences of those suggestions would be in terms of family situation or for her client. I can't handle him on my own.]

While most mothers agreed that they wanted to be involved in intervention and transition planning, there was a lot of variation in the level of involvement. Some mothers were content in having a minimal role and trusted the professionals to take the lead. Other parents wanted to have an active role and participate in a lot of the decision making. Most parents felt that a balance between two extremes was most helpful, but they were not always able to achieve that balance.

[They involve us a lot. But there comes a time when I don't want to be involved in everything. I think they need to do their work too, in the sense that I don't have the time or energy to be part of every single strategy. Some need to involve me but others, I think, 'Ok you take care of him now'.]

Some parents had the perception that parental involvement was only encouraged when it was to the benefit of the professionals or the organization. One parent gave an example of being solicited to participate in various fundraising events. When it came time to intervention planning, however, she reported that she was completely ignored. Parents who had negative experiences with regards to their involvement expressed that professionals do not want the input of parents because it “leads to trouble”.

[The school allows the parents to be involved, but they don’t really let them become involved because involved parents are a synonym for problems for the school. Because when parents get organized, it’s a problem for them (the school).]

Transition Planning. Transition planning was almost inexistent in the present study. A few mothers spoke of their child’s transition from elementary to high school. Mothers reported that the most helpful practice was when the child could go visit their new school and meet their teachers. Mothers did not report having formal meetings with professionals from both schools. As such, they were responsible for informing the new teachers and educators about their child. One mother reported that she contacted the new professionals to ask for a meeting at the start of the new school year. She wanted to be proactive in informing the professionals about her son’s difficulties. She was shocked by the interaction.

[I asked for a meeting and she asked me why. I explained that it was to present my son and explain who he is. She answered me, rather rudely, saying, ‘I know your son’. I said, “Really, how?” and she said she read his file. I told her that she didn’t know him and that I wanted to share my knowledge and she answered, ‘I don’t need your advice’. Wow...just wow.]

The mothers who spoke about the transition into adulthood shared that it would “only be starting when the child was 20”. Mothers expressed frustration as their child could not be placed on waitlists for adult services until the age 20.

Solutions

The codes in this category were solutions offered by parents to help improve service access and delivery. This core category consists of two sub-categories: Relationships Between Parents and Professionals and Services. The sub-categories and the tier-level codes can be seen in more detail in Table 5. This category accounted for very few codes. Despite being asked how they would change service delivery, few mothers offered solutions. For most mothers, their focus was on their own stressors and how to resolve them in their own individual context as opposed to more widely.

Table 5

Sub-categories under Solutions in Study 1

Core Category	Sub-Categories	Tier-Level Codes
Solutions	a. Relationships Between Parents and Professionals	i. Increased communication ii. Increased collaboration
	b. Services	i. Continuity of services

- ii. Increased funding
 - iii. Increased services
 - iv. Parent workshops/training
 - v. Easier access to information
 - vi. Proactive services and interventions
-

Relationships between parents and professionals. Mothers reported that improved communication and collaboration with professionals would facilitate their experiences. Though almost all of the mothers in the study reported at least one positive relationship with professionals, they explained that professional practices were never consistent. This varied in terms of the professionals' communication style, their level of knowledge and experience with children with ASD, their involvement with the family, and their openness to involve parents in intervention planning. Parental involvement was important to mothers, and they experienced varying levels of involvement depending on the professionals. Though they recognized that individual characteristics would vary from professional to professional (e.g., personality traits, general demeanor), mothers wanted consistency across services in terms of their level of involvement and follow-up, interventions, and level of parental involvement.

[A friend of mine has services from the same place but it's totally different. She (educator working with her friend) follow-ups and actually knows what she's doing. I have to fight to get anything and she (educator) never gets back to me. Like how is this so different? It should be the same, it's from the same center!]

Services. One of the most frequently reported solutions was easier access to information about services and interventions. Mothers proposed workshops, information packets given following the diagnosis, and a repository of services that parents could access.

[How great it would be to have an online service bank. You enter, 'ASD need help' or 'services in my region' and boom! That, oh my God! It would hardly cost anything and would be centralized. It would avoid spending millions otherwise and would avoid pain, tears, and suffering. It would be the best thing to do, in my opinion.]

Families need more services, not only for their child, but for parents as well. Parent training on how to intervene with their child; teaching them about topics like sexuality and health; and financial and legal planning for the future (e.g., guardianship, wills, welfare applications) were also cited as possible solutions to help improve parenting stress. Moreover, mothers reported wanting services to be more proactive in planning for the future. As was described earlier, very few parents reported having transition planning and support in planning for their child's future.

[The lack of preparation needs to change. Once they turn 16, you seriously need to start sitting down and concretely making plans, not waiting until they are 20. Then, it's just way too late.]

Constructed Theory: The Parents' Perceptions Theory

Constructivist Grounded Theory approach leads to the generation of a theory that is an interpretation of the studied phenomenon as opposed to an exact representation (Charmaz, 2014; Sebastian, 2019). This interpretation results from interactions between the researcher, the participants, and the data, and takes into account the researcher's prior knowledge (Charmaz, 2014). The Parents' Perceptions Theory was constructed from the present data. This theory posits that parents' stress arises not only from the lack of services, but also from their perceptions of the usefulness of the services, specifically, whether the services or clinical practices are addressing their needs, or their child's needs.

In the present study, mothers reported distress due to a general lack of services. However, distress was still present when they received services. Mothers' perceptions about the support being offered appeared to be an important factor. Support in this study was defined as services (e.g., behavioral interventions, placement), information (e.g., information about resources), emotional support (e.g., validation), helpfulness (e.g., services address parent or child's needs), and tangible support (e.g., funding). When the mothers perceived a lack of support in any of these aspects, they experienced distress, even if they were currently receiving services. Thus, it is not only a lack of services, but mothers' perceptions that explained the stress they experienced. Further, it was not only the services, but also the clinical practices. This included parental involvement, following-up with parents, intervention planning, and general collaboration with professionals. If mothers perceived that their needs, or their child's needs, were not being addressed by the service or clinical practice, they reported distress.

There was substantial evidence for the Parents' Perceptions Theory in the data. Mothers had to jump through numerous hoops to access services for their child. At times, these services were helpful and met the parent or child's needs. A common complaint expressed by mothers was the lack of fit between their expressed need and the intervention. Mothers reported significant frustration when the services failed to address the needs of the child or mother. Examples were provided whereby a professional would work on communication by creating a visual schedule. Mothers would inform the professional that the strategy had been used before and they needed something more, yet the professional maintained that intervention.

With regards to information, many mothers reported asking professionals for specific information about resources and intervention programs. Professionals varied in their responses in that they either did not follow-up with the mothers, provided them with information that was different than what was requested, or told mothers that the services were not necessary.

Emotional support was sometimes found to be lacking as mothers felt invalidated and not heard. The communication between mothers and professionals was not always supportive. At times, professionals spoke "down" to mothers and failed to acknowledge their expertise with regards to their child. Parents reported feeling judged by professionals that blame them for their child's difficulties, or for not being more invested and involved in interventions. In these instances, mothers frequently reported that stress was elevated as the professionals were not addressing their emotional needs.

Finally, perceived lack of tangible support was also present. Mothers reported receiving some funding from social services organizations. While funding can help temporarily ease financial strain or allow parents to access necessary private services, mothers felt that it was unhelpful as they were not able to use the money for what they needed.

These examples highlight the Parents' Perceptions Theory in that merely receiving services is not enough to support these families. Rather, the needs of the families need to be

evaluated to identify the appropriate resources to address those needs. The findings demonstrated that, at times, needs can be met with a specific service (e.g., behavioral interventions) but that they can also be addressed by certain professional practices by clinicians (e.g., following up, checking in on parents, parental involvement).

Study 2

The aim of Study 2 was to investigate if the themes from Study 1 would be found in a group of younger parents with ASD. To do this, the coding scheme developed in Study 1 was used to code interviews with parents. The findings from this study demonstrate that three of the four major themes present in Study 1 were endorsed by these parents (refer to Figure 4 below). The Solutions theme did not emerge from this data set.

Similar to Study 1, the category Parent Stressors accounted for the largest percentage of codes in the study, followed by Professionals. There were very few instances of the Services code. Further, the Solutions category that was present in Study 1 did not emerge in the current data set.

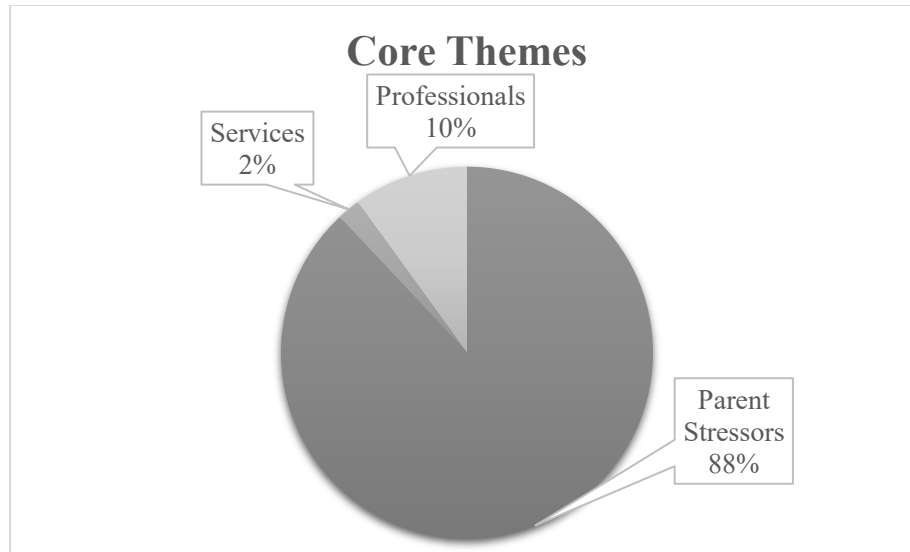


Figure 4. Core themes in Study 2.

Parent Stressors

This core category consisted of eight sub-categories: Unmet Needs; Child-Related Stressors; Daily Hassles; Emotional Stressors; Service-Related Stressors; Emotional Reactions; Extra Roles; and Buffers of Stress. The sub-categories and the tier-level codes for Parent Stressors can be seen in Table 6.

Table 6

Sub-categories under Parent Stressors in Study 2

Core Category	Sub-Categories	Tier-Level Codes
Parent Stressors	a. Service-Related Stressors	i. Staff turnover ii. Turning to private services iii. Lack of services for child iv. Fighting for services/Advocacy v. Paperwork

	vi.	Waitlists
	vii.	Obstacles
	viii.	Timing of services
	ix.	Appropriateness of services
b. Unmet Needs	i.	Services for child/family
	ii.	Access to information
c. Child-Related Stressors	i.	Behavior problems
	ii.	Communication
	iii.	Health-related issues
d. Daily Hassles	i.	Transportation for child
	ii.	Home-related stressors
	iii.	Financial
	iv.	Employment
	v.	Family schedule/organization
e. Emotional Stressors	i.	Concerns about child's present/future
	ii.	Parent aging
	iii.	Social isolation
	iv.	Marital problems
	v.	Mourning child's disability
	vi.	Judgement of others
f. Emotional Reactions	i.	Anger
	ii.	Guilt
	iii.	Sadness
	iv.	Feeling invalidated
	v.	Frustration
	vi.	Happiness
	vii.	Anxiety/worry
g. Extra Roles	i.	Supplemental services provider
	ii.	Care coordinator
h. Buffers of Stress	i.	Other parents/professionals

Service-Related Stressors. Similar to Study 1, service-related stressors were the most reported stressors. Waitlists were a universal complaint of parents. Parents reported waiting months to years for services. At times, the waitlists were so long that children “aged out” of services. For example, following a formal diagnosis, a child was placed on a waitlist for Applied Behavior Analysis (ABA) at the age of 4.5. Such services are only offered until the age of 6. The child was on the waitlist for so long that by the time it was his turn, he was no longer able to receive services because he was “too old”. As in Study 1, some parents reported having to rely on crises to be able to have access to services. That is, parents shared that there was an important pivotal crisis that led to the start of services. One mother reported that she received services after an incident where her child displayed aggressive behavior that broke two of his educator’s teeth.

[I waited for years to see the child psychiatrist. But after he broke her (educator) teeth, I was seen within two weeks! Who knows how much longer I would have waited? But

that's the sad reality for parents (of children with ASD). It takes situations like this to get things moving.]

This phenomenon appeared to be quite common as several parents reported similar examples. In fact, one mother shared that she had been advised by another parent to tell her social worker that she was having a breakdown to help speed up the start of services. Further, a similar approach was also used by other professionals. One mother shared that one of the professionals working with her son decided to close his file because it was the only way another, more urgently needed, service would open the child's file at their organization. Despite this, the family was left without any services for a year.

Many parents reported turning to private services due to long waitlists. The services that were most frequently sought privately were diagnostic evaluations, speech therapy, and behavioral interventions (e.g., ABA). Seeking private services for a diagnosis was especially important for most parents as they realized that they could not even be placed on waitlists for specialized services without a formal diagnosis. Once the diagnosis became formal, parents who could afford private services found private ABA services as they knew their child might age out of services, especially when the child's diagnosis was given after four years of age.

As was seen in Study 1, parents reported having adversarial interactions with service providers due to constantly "fighting" for services. Parents have to continually advocate for services at every step of the process from diagnosis to entry into the school system. One parent stated,

[They told us they would be there for him, 100%. But then two days later, the CRDI pulled out because the teacher said she could do it on her own and then they wanted to close his file! So they aren't there for our son, but just to teach the teacher. It's like, will we ever get out of all of this, my God. It just grinds at you and you always have to fight for everything.]

Further, parents not only have to fight with service providers, but also other organizations such as insurance companies to be reimbursed for the costs of their child's. One mother described her life as a "constant battle".

[It's a constant battle for everything. You wake up in the morning and it's a battle with your kid, then it's a constant battle with the insurance company to get my reimbursements, constant battles with the Quebec government, NON-STOP, who ask for paperwork for this, paperwork for that, who then refuse you. So you fight to get it back and they give it back to you, but then refuse again and you have to take it to the administrative tribunal. It's a constant battle for everything.]

Parents expressed frustration with the timing of services as they ended prematurely due to specific criteria (e.g., allotted number of sessions, age of the child) established by the organizations. One mother shared that her son had slowly begun showing improvement following a block of intervention. The service was terminated as a result of these improvements even though the skills acquired had only been present for a short time. She shared,

[As soon as things got a bit better, even if it's not for long, they close the file. And it really sucks because he is going to high school next year and we are not going to have anyone to help us. But they have no choice because the waitlists are too high.]

Sometimes, it was not that the child was doing better, but that the parent was “too equipped”. This mother reported that she had taken advantage of various parent coaching workshops and often sat in on her son's therapy sessions to learn ways to manage his behaviors and teach him new skills. She recalled a recent interaction when she learned that her son's services were going to be terminated. She felt that her son still needed the service. She explained,

[When I said it was too early to close, do you know what his educator said? ‘You are too well equipped’. Because I went to all the conferences and trainings, well, I'm penalized. Like come on!]

In addition to terminating early, many parents reported not having access to services when they needed them. This not only applied to services like early behavioral interventions that occur in a specific range of time (e.g., under the age of 6), but also for emergency services. A mother shared her experience in which her child was expelled from daycare due to problematic behaviors. As a working mother, she had to find alternative arrangements, but was having difficulty due to her son's ASD diagnosis and related behavioral issues.

[A friend of mine who has a child with ASD said, ‘Go to the CSSS crying, that will get you services. You really have to show that you are in distress.’ So I said, Ok, I can do that. I was really upset, he was kicked out and I couldn't find another daycare and I had to work. They took my name and it took them six weeks, but by then I was like, ‘Crisis is over, it's done’ so we got nothing from them. So we had to figure it out by ourselves.]

Endless paperwork, staff turnover, and service criteria were reported as additional stressors related to service access. With every new request for service, parents had to complete lengthy paperwork, the purpose of which was often unclear to parents. Further, parents reported not having access to what is needed for the applications and services being delayed due to a forgotten form. Frequent staff turnovers resulted in parents having to re-tell their stories multiple times, a process that was bothersome and frustrating to parents. Further, criterion-based services were an important source of frustration as families could be denied services due to language, child's age, diagnosis, and/or level of functioning, or location. One mother captures this experience well with the following statement:

[They tell you can make your request and then they say, ‘Oh do this’ or ‘He's not autistic enough’, ‘He's not enough this, he's not enough that’, ‘We are missing this document’, ‘If he is better, the service stops’. And if you want services, you have to do this process over and over again but you're already exhausted. You don't want to start over and tell your story for the hundredth time. And it's like that with every service, the CSLC, the CRDI, the government, you are constantly repeating your story.]

What was most frustrating for parents is that even when they jumped through all of these hoops and received support, the services themselves were deemed to be unhelpful. In such cases,

parents reported that the services did not meet the needs of their child or their family. That is, services employ a “one size fits all” method to its recipients. One mother shared her experience,

[Well, the waiting lists are very long for any kind of service. And when you get there, you realize that they’re not going to be really helpful, so that’s kind of frustrating because I was waiting for support services for three years. And when I got it, the person didn’t really understand what we were going through. And she wasn’t willing to help us the way we thought she would.]

Unmet Needs. Similar to Study 1, most parents reported needing more services for their child with ASD. Unmet needs consisted of a general lack of services for the child and family, and difficulty accessing information about the services available and how to apply for them. Parents reported a variety of needed services including therapies (e.g., speech, behavioral, occupational), evaluations, transportation, respite, medical support, and leisure/socialization. The most commonly cited needs were psychological evaluations to obtain a diagnosis and behavioral intervention. Another prominent need was transportation services. One parent reported that she had been driving her daughter to and from school for the last four years as her daughter was unable to have access to adapted transport services. She stated, “I cannot work because I have to stay home for her. I spend three and a half hours a day in a car, so that’s a big stressor for me.” Another mother echoed this stating, “I can’t work as much as I would like and need to because I spend half my life bringing him to appointments.”

Further, parents reported needing support for themselves. This took on different forms including emotional support (e.g., psychological services), instrumental support (e.g., babysitting, house cleaning), and psychoeducation on how to communicate and work with their child with special needs. Further, some parents expressed the need for services for their child’s siblings. The child’s siblings often received less attention as parental attention is on the child with ASD. As a result, parents reported feeling guilty for having difficulty attending to all of their children’s needs equally.

[You know, we can’t give everything to one and nothing to the others. It’s a major stress dealing with other children, too. It’s very hard. What ended up happening is that the spotlight was so much on (child with ASD), that she (sibling) started acting out. She started feeling, not left out, but as though she was less important. It really sucks.]

Accessing information about services was another struggle for parents. Many reported spending hours researching services for their child. Parents shared that information was not readily available on websites and they often had to call different organizations. Even when they did so, some parents reported that the person they spoke to did not know about many existing services. When parents had access to a social worker to help find and coordinate services, some parents reported frustration that the social worker would not present all the information. Rather, parents were expected to “ask for what they want”.

[She (social worker) told me, ‘You just have to ask’. Well, of course, but what if I do not know that it is something I can ask for? They need to understand that I do not know what’s out there. They think we will just ask for what we want but how do you

want us to know when the information is not shared and you can't find out anything?]

Child-Related Stressors. Similar to Study 1, the biggest child-related stressor for parents was behavioral difficulties such as physical aggression (e.g., biting, hitting, kicking, scratching), screaming, oppositional behaviors, inattention, and requiring constant supervision. It was not merely the presence of the behaviors that were stressful for parents, but also that most parents felt they lacked the necessary skills to manage the behaviors. Some of the behavioral difficulties were reported in tandem with communication difficulties. Parents observed that their children would begin to act out due to problems with communicating their needs or with understanding what others are asking of them.

[From the ages of 2 to 4, she was very physically aggressive. She couldn't understand what we were saying or tell us what she wanted. She was very frustrated, and she took it out on us...with a lot of therapy, her communication is better and her behaviors are almost gone.]

Parents reported their own frustrations with their child's communication. Feelings of hopelessness were expressed when parents were unable to understand their child and would see their child's behavior deteriorate as a result. Frustration was compounded as speech therapy services appeared to be especially hard for parents to receive, thereby not allowing parents to see a light at the end of tunnel. In addition, sleep and feeding difficulties were reported by many parents. Children were found to have significant difficulties falling and staying asleep. As such, parents reported sleeping a few hours a night and often feeling fatigued. With regards to nutrition, parents reported that feeding their child was a struggle. Children were described as "picky eaters" and parents were worried that their children might be not eating enough or getting adequate nutrition.

Daily Hassles. Financial difficulties were the biggest daily hassle reported by parents. Some parents are unable to work as they have to care for their child (e.g., transportation, attending appointments). Parents shared that though they did not have the means to do so, they still pursued private services for fear that their child's development would be compromised, thereby adding to the financial strain. Some parents had other caregiving responsibilities (e.g., other children, caring for elderly family members) that added more obligations to an already hectic schedule. As discussed previously, transportation of the child to and from various appointments added to the parents' busy daily schedule. Difficulties related to employment included rigid work schedules and lack of employer understanding. Further, some parents reported increased stress as a result of trying to juggle their work and family obligations.

Routines and family organization was important for families. Parents highlighted the importance of creating and maintaining specific routines to allow the day to "run smoothly". Deviations from those routine lead to chaos and an increased risk of tantrums or other behavioral difficulties. One mother shared that she is in constant "crisis prevention" mode.

[I am the spinning top in my house that does everything at once so that the routine goes smoothly and calming down crises and preventing them...I always have to be one step ahead and it's hard and exhausting.]

Emotional Stressors. Parents endorsed worry about their child's present and future. In the short-term, parents' worries are related to their child attaining certain skills, reducing behavioral problems, increasing communication and socialization. In the long-term, parent worry about what their child's future will be. Parents question if their child will be able to have some independence and whether certain difficulties will improve (e.g., behavior problems). Even though the children in this sample were under the age of 12, parents were already thinking about what would happen when they would no longer be able to care for them.

[I am afraid of the future because parents will go one day, so he has to be able to wash himself, to wash his clothes, clear the table, you know things like this for everyday life. So it's a challenge. I want to think of now but... hmm the future. I don't worry about an actual day, but his whole future...yeah, I'm afraid.]

At times, these worries were accompanied with grief. Some parents reported that they were still mourning the loss of their "perfect child" and accepting the diagnosis. One mother shared her feelings of grief.

[I started grieving for a child that died. And for me, what's hard is that it is never over. It will never be over. And the fear... what can you do to outlive your child? Because she will never be independent, you will always need to be there to take care of her. I think that's the biggest stressor and it hasn't changed.]

Isolation was reported by parents in the study. Due to lack of time, finances or the child's behavioral difficulties, parents did not often go out into the community or partake in leisure activities. The effort and time required to prepare their child for the outing outweighed the benefits of the outing. One mother expressed that she and her husband tried to engage in leisure activities with their young children. She acknowledged that outings served as learning opportunities for her children but felt exhausted due to the amount of time and preparation involved. She recalled a weekend when they were getting ready to go see a movie as a family.

[I know how long it can take to get them out the door. Just the everyday routine is stressful! Like sometimes, we were trying to get out the door to see a movie and it took two hours of tantrums to even get out the door. My husband said to me, 'God! Why do we even try to do things like this?' But at the same time, he'll (son) never learn how to do things if we don't. Its extremely exhausting.]

Another contributing factor to the isolation of these families is the fear of judgement from others which was almost universally endorsed by parents. Parents feared being viewed by others as "bad" or incompetent parents. They worried that their child would be viewed as a "spoiled brat". They believed that since their child appears physically "normal", there are no signs to others that their child has a condition which might explain their behaviors. As such, this elicits more judgement than if the child had a noticeable disability. During outings in the community, parents felt as though "all eyes are on them". They received dirty looks and heard exasperated sighs from others when their child was having a behavioral outburst. One mother described it well.

[You're often seen as a "bad parent" and sometimes people will tell you that to your face. It's people giving you side eye and we don't deserve it, not at all. People think that I have a spoiled brat because of his reactions. It's really not fun.]

In addition to the judgements and looks from others, parents received unsolicited advice from others. Family members, friends, and individuals provided parents with intervention strategies they would apply if "this was their child". These strategies often insinuated that the person would be able to change the situation and failed to consider the nature of the child's difficulties. Parents reported feeling not only frustrated by the unsolicited advice but feeling as though they were being blamed for their child's behaviors. One parent shared an interaction between her and her cousin.

[The worst is the judgement of others. People look at you like, 'Do something!'. Like, last summer, my son would not get in the car after a family party. My cousin was there and said, 'Do you want me to grab him and put him in the car. You can bet he's going to listen to me!' It's ridiculous.]

Emotional Reactions. Frustration was the most reported emotions for parents. Parents were frustrated due to lack of support, guidance, and services. Parents were frustrated with long waitlists, constantly advocating for services, judgement from others, and perceptions that their needs are going unheard and unmet. Further, frustration arose from negative interactions with others (e.g., family members, friends, professionals). Parents reported feeling as though their experiences or struggles were not being validated others. Moreover, they were sometimes blamed for their child's difficulties despite their best efforts at managing their situation.

[The hardest part is trying to convince everyone around you that you are not crazy or overreacting, and that it's not your parenting. He's so little and we got so many comments and feedback from random people in public saying things like, 'If my child... blah, blah'. It's hard when you're really struggling and doing everything you can, maxing out resources and getting no help and people are constantly blaming you. Like, I'm doing everything I can. There's just no help.]

Another parent expressed frustration that the caregiver impact does not "let up". Though their children might age, the level of care involved is more akin to that of a much younger child. She spoke of her 8-year-old son who required constant supervision.

[He can't do anything for himself, so it's constantly watching making sure he doesn't hurt himself. So for most parents, this stage would be, I don't know, a year or so? Well, he's 8. It's not any one event, it's wall to wall, 24/7, without a break. The challenge is having a newborn for 8 years.]

Frustration and worry were often reported together. Watching their child continue to struggle without any supports to help them was particularly frustrating for parents. Some parents were quite proactive in finding and applying for services but were halted by waitlists.

[I have to wait for services. I have to wait and that's the hardest thing as a parent. You see the years go by and I can tell you that deep down, I know that if I could be with him at school with the required training, he would be talking a lot more than he is now. I hit a wall and it's killing me.]

Extra Roles. In addition to their roles as parents, caregivers adopted other roles to help their children. Parents became educators and teachers. Parents implemented behavioral management strategies and taught their children life skills (e.g., getting dressed, brushing their teeth). They developed visual schedules and pictograms to help their children learn. One parent explained an intervention strategy she taught her son.

[I use an image I found of a volcano and the lava goes up and down depending on how intense the emotion is. Bit by bit, by verbalizing these emotions with him, we noticed that his anxiety got better. It really helped him.]

In addition, parents worked on communication and socialization. Parents taught their children pre-academic and academic skills. These roles were not only taken on while waiting for services but were also used to supplement existing services. This was especially the case when parents felt that the services were not addressing certain needs or difficulties.

Buffers of Stress. Other parents of children with disabilities served as buffers of stress for parents. These individuals provided much needed guidance with regards to services available, intervention strategies, and connecting parents to community resources. In addition, these veteran parents were able to validate parents' experiences and feelings as they had gone through similar things. Another source of informal support were friends or acquaintances that worked in the social service system. One parent had an acquaintance who was a social worker who put her in touch with a colleague in another service. She explained,

[I was lucky enough to know somebody who knew, and somebody who knew someone who could lead me in the right direction. Before that, I would spend hours on the internet researching services in our area that were in English.]

Services

This core category consisted of two sub-categories: Large Caseloads of Professionals and Funding. The sub-categories and the tier-level codes for Services can be seen in Table 7.

Table 7
Sub-categories under Services in Study 2

Core Category	Sub-Categories	Tier-Level Codes
Services	a. Large Caseloads of Professionals	
	b. Funding	i. Lack of adequate funding
		ii. Poor distribution of funds

Large Caseloads of Professionals. Parents were simultaneously frustrated by and comprehensive of the fact that professionals were carrying heavy caseloads. Due to large workloads, parents expressed frustration that they were not getting what they needed. A mother reported that, for a period of time, her son began hitting others in his classroom. Her son's teacher was so overwhelmed with other students that she was unable to take care of him. Specifically, the teacher stated that she "did not have time" to deal with her son's behavioral issues and sent him home.

However, parents sometimes excused the professionals' absence or lack of follow through by acknowledging that their caseloads were "too heavy". One mother recognized that a teacher made substantial efforts to help her son, despite having a large classroom and a lack of resources. She stated, "He has such a great teacher, but she is overwhelmed with work, lacks training, and she has too many students."

Funding. Parents expressed a lack of funding for services and poor distribution of funds. There was not enough funding provided to parents to help cover the costs of therapies, respite, or equipment and materials (e.g., diapers, specialized locks). In addition, parents believed that organizations and schools were not receiving enough money to provide adequate services due to frequent budget cuts. This led to children receiving "half services". For example, a school might not have the necessary funding to pay for full hours of speech therapy services. As a result, the services are adapted in one of the following ways: group speech therapy sessions, a very limited number of individual sessions, or support to the teachers to use the strategies in the classroom.

Some parents reported that money was not distributed properly by the government. One father expressed frustration that money was being allocated for research and genetic testing instead of services that could directly benefit children and their families. With regards to the school system, several parents spoke of their child's hours being shared with or allocated to other children. One mother described a situation whereby her child was entitled to 8 hours of individual educator support a week. She discovered, however, that the educator would also often assist another child in the classroom during that time. She believed that the school did not have enough funding and attempted to help the other child in this way. While she understood and empathized for the other child, she felt that her son was missing out on a service he needed.

Professionals

This main category consisted of four sub-categories: Experience, Information, Knowledge; Communication; Motivation; and Collaboration. The sub-categories and the tier-level codes for Parent Stressors can be seen in Table 8.

Table 8

Sub-categories under Professionals in Study 2

Core Category	Sub-Categories	Tier-Level Codes
Professionals	a. Experience, Information, Knowledge	i. Lack of experience/expertise
		ii. Appropriate experience/expertise
		iii. Poor knowledge of services
	b. Communication	i. Providing and sharing information
	c. Collaboration	i. Following up
		ii. Parental involvement
		iii. Relationship quality

d. Motivation

Experience, Information, Knowledge. Professionals were seen as lacking experience and knowledge with ASD. They lacked knowledge about the diagnosis and its related difficulties. This was especially the case in school settings, and less likely in more specialized tertiary care organizations. Parents reported that, as a result of their lack of experience, professionals would have a “one size fits all” approach to intervention planning. That is, they would use a limited number of intervention strategies that were not individualized. One parent was so fed up that she reverted to home schooling.

[We left the public system. We didn’t want to be in a system that put children with autism in a box and it was ever since then that she began to develop and improve. I started three years ago and she has really advanced since then.]

Limited experience and knowledge also lead to clashes between parents and professionals on appropriate intervention goals. One parent reported that the educator in her classroom had limited experience with children with autism. She expressed being shocked during a parent-teacher meeting when she saw the type of work her daughter was doing in class.

[She (educator) showed me some of the worksheets that my daughter was doing. They were so proud of her and I was like, what? She’s been doing that kind of work for years! They had no idea how to stimulate her and work with her.]

Other difficulties arose when the interventions failed to take into account other aspects of development. In most cases, interventions were centered around behavior management and teaching life skills, often at the expense of academics. One mother shared that at the start of the school year, her son’s Individualized Education Plan (IEP) consisted solely of goals related to behavior management with no focus on academics.

[They (teacher and educator) said that at the start of the year, they needed to manage his behaviors and that academics were not important. But then, at the end of the year, they were like, ‘He’s failing, his academics are poor.’ It’s like come on, he needs both.]

A few parents cited having experienced and knowledgeable professionals. In these instances, intervention goals were often individualized to the child and family; multiple intervention strategies were used; professionals were flexible in their strategy use when an intervention was not working; and the child often had successful intervention outcomes.

Communication and Collaboration. Overall, parents reported positive relationships with professionals. Successful relationships with professionals were characterized by open communication, information sharing, parental involvement, collaboration on intervention goals, and feeling supported by the professionals. Most parents had at least one professional with whom they had a positive working relationship. Parents acknowledged the importance of these relationships and viewed professionals as essential team members in helping their child progress. Further, they recognized the importance of having a good “fit” between the professional and the family.

[At the end of the day, their (child) progress depends on the people who worked directly with them. And if it's not the right person, if they are not able to create a connection with the child, then nothing will help.]

Parents appeared to understand the limitations of the professionals working within the system. Most parents acknowledge that professionals were doing their best. They recognized that that professionals had to work within a system that created limitations such as service delivery protocols (e.g., only being able to offer a limited number of sessions) and lack of resources (e.g., funding, personnel, space).

Negative relationships were characterized by poor communication, lack of follow through, lack of parental involvement and poor collaboration on interventions. One of the more frequent complaints was a clash between the professional and parents on intervention goals. In these relationships, the professionals appeared to assert themselves as the “experts” and would not acknowledge the parents’ intimate knowledge of their child.

[They try to do it their way, without taking into consideration that he's autistic. They try to do it as though he's a neurotypical child. Sometimes when he has a hard time in the classroom, they would take him out of the classroom, and this has been going for two years already and it's not working. So, for me, I say it is not working, why would you still do that? We have to find ways to deal with the problem without doing the same thing every time, all the time, you know what I mean? So, for me, I try to tell them if it's not working, then let's try something else, but they don't listen. They shut me out because I'm just his mother.]

Evidence for the Parents' Perceptions Theory

The Parents' Perceptions Theory was evident from the data in Study 2. The questions from Study 2 were more general in nature than those posed in Study 1. Despite this, very similar themes emerged from the parents in Study 2. Parents' expressed frustration due to difficulties accessing services. However, their perceptions of the support and clinical practices also influenced their reported distress. Similar to Study 1, support was defined as services (e.g., behavioral interventions), information (e.g., information about resources), emotional support (e.g., validation), helpfulness (e.g., services address parent or child's needs), and tangible support (e.g., funding). Parents in the present study shared their stressful experiences with long waitlists and criterion-based services. These parents struggled with having adequate information about the types of services available, how to apply for services, and finding the necessary finances to help pay for their child's essential services (e.g., speech language pathology, early behavioral interventions). However, parents also expressed frustrations with services that did not address their needs or clinical practices that made them feel inadequate or invalidated. Parents who were currently receiving services reported that they were unhelpful as they were not addressing their child's needs, or their own needs (e.g., for example, support for their own emotional difficulties). As was seen in Study 1, merely receiving services does not alleviate parents' reported levels of stress. When the services or clinical practices were deemed unhelpful, distress was still present for these parents regardless of actual service delivery. The theme “Solutions” that was present in Study 1 was not found in Study 2. This could be because parents were not explicitly asked how they would change service delivery. However, it could also be explained by the age group of the

children. Children in Study 2 were younger than those in Study 1. It is possible that, with younger children, parents are more preoccupied with aspects such as coping with a new diagnosis and obtaining services for their children.

The presence of the Parents' Perceptions Theory in Study 2 validates its importance. The questions asked during the interviews in Study 2 were more general in nature than those asked in Study 1. Despite this, evidence for the Parents' Perceptions Theory was still prominent throughout the interviews. Further, the population in Study 2 was parents of younger children with ASD who were not necessarily undergoing a transition. Parents' perceptions greatly influenced their reported levels of distress despite these differences. This helps highlight a significant gap in the services for families of children with ASD. Parents must be consulted about what they require and what their child needs. Many parents reported professionals being the "principal" decision makers. While professionals have their own important expertise, the goal of the services are to help support the family and the child. If their needs are not being met, the service is not helping or alleviating parent distress.

Discussion

Understanding the experiences of families with accessing and using services has been an interest of researchers for some time (e.g., Baker-Ericzén et al., 2005; Rao & Beidel, 2009). While research has elucidated the stressors experienced by parents, less was known about their lived experiences in accessing and using services during different transitional periods including the transition around diagnosis and the transition from high school to adulthood. In Study 1, 78 mothers of adolescents with ASD were interviewed about their experiences with regards to services access and use during one of two time points: The transition from elementary to high school or the transition from high school to adulthood. Four core themes emerged from the data: Parents Stressors, Services, Professionals, and Solutions. The Parents' Perceptions Theory emerged from the lived experiences of these mothers and demonstrated that their perceptions about the support being offered played an important role in their reported levels of distress. Support included services, information, emotional support, helpfulness, and tangible support. The Parents' Perceptions Theory stipulates that when there was a perceived lack of support in any of these aspects, mothers reported distress, even if they were currently receiving services. Thus, it is not only a lack of services that can lead to reports of stress, but mothers' perceptions of the support received.

In Study 2, the coding scheme developed in Study 1 was used to analyze the interviews of 20 parents of younger children with ASD (ages 2-11) to explore their experiences with service access and use. The results demonstrated similar themes to those found in Study 1. The only exception was that the category, "Solutions" did not emerge from the data. This is likely because the specific question in Study 1 that asked parents about what they would do to improve services was not asked in the second study. Further, the children in Study 2 were younger than in Study 1. As such, it is possible that these families were preoccupied with adjusting to their child's diagnosis and on finding services. As such, these parents were more focused on these stressors and did not spontaneously offer solutions. Evidence for the Parents' Perceptions Theory was found in Study 2 as parents' perceptions of services were found to influence their reported levels of stress.

The results of both studies contribute to the existing literature on parenting stress in several ways. The constructed theory, the Parents' Perceptions Theory, has important implications for research and clinical practice. Understanding that parents' perceptions of

support impact their reported levels of stress could be the key to helping these families alleviate their distress. The present studies demonstrate the advantage of exploring phenomenon not only from a quantitative perspective, but also qualitatively. In Study 1, the specific methodology led to the emergence of the Parents' Perceptions Theory. The systematic yet flexible approach used in Constructivist Grounded Theory allowed the researcher to identify the emergent theory and better understand the experiences of mothers. It helped to elucidate why parents who are actively receiving services continue to report distress. Study 2 helped validate that the Parents' Perceptions Theory was also present in parents of younger children, demonstrating the importance of understanding parents' perceptions to better tailor service delivery and service goals.

Previous studies have shown the importance of perceived levels of social support as opposed to actual support (e.g., Ke et al., 2010; Siedlecki et al., 2014). Indeed, subjective rather than objective (e.g., perceived social support vs. actual social support) evaluations of support appear to have superior validity in predicting psychological well-being (e.g., Ke et al., 2010; Siedlecki et al., 2014). In parents of children with ASD, perceived informal social supports have been found to have a positive effect in alleviating stress (Drogomyretska et al., 2020). The Parents' Perceptions Theory adds to this literature by stressing the importance of understanding parents' perceptions of service access and educational interventions. Existing literature has identified four categories of support that are salient to parents of children with ASD: a) emotional support (i.e., support with managing emotions); b) physical support (i.e., relates to activities of daily living); c) material and instrumental support (i.e., financial resources or help carrying out tasks); and d) informational supports (i.e., access to information or knowledge; Kyzar et al., 2012). This literature, in combination with the findings from the present studies, lead to the argument that it is not just perceived social support, but also perceived services, information, helpfulness, and tangible supports that are important. When parents perceived that any of these categories were unhelpful or negative, they reported distress. This highlights the importance of not only looking at objective reports of stress, but at parents' perceptions. Further, all aspects of perceived support should be examined, not just emotional/social supports. Parents expressed the need for most of these supports, but especially material and informational supports. As unmet services needs are significantly related to caregiver strain, ensuring that families have access to these supports can be the key to reducing the impact of parenting stress (Shivers et al., 2017).

In addition to the creation and validation of the Parents' Perceptions Theory, the present studies added support for findings from existing research. Previous literature has demonstrated that levels of caregiving impact and stress vary over time and developmental milestones (e.g., Yu et al., 2018). Although ASD is a lifelong condition that impacts the family, the specific demands related to certain milestones will wax and wane, whereas the aspects related with caregiving impact regardless of a transition (e.g., behavior problems) appear to be relatively constant (Yu et al., 2018). Moreover, more specific demands, such as transition-related demands, have been found to be the stronger predictors of caregiver impact than general stressors (e.g., daily hassles; Yu et al., 2018). Indeed, there were clear stressors that were related to the specific age groups and milestones. Parents in Study 2 expressed more frustrations with evaluations to obtain a diagnosis, whereas mothers in Study 1 sought support in transition planning and appropriate supports for their adolescent/adult children. Further, while all parents reported some daily stressors, these were not reported nearly as often as diagnostic and transitional-related stressors. Despite these differences, there were clear stressors that persisted across both groups including

child behavior difficulties, lack of services, waitlists, and worries about the child's future. This highlights the need for early and continued intervention supports for these families, as needs persist throughout the child's lifespan.

The Parents' Perceptions Theory demonstrated that services can help reduce parenting stress, so long as they address the child's or the parents' needs. However, parents reported not only a lack of services in general, but a lack of services for siblings of children with ASD or for themselves. Parents reported wanting more services to teach them how to interact, communicate, and work with their child. Offering such training would be a type of problem-focused coping which has been found to decrease depressive symptoms and improve mother-child relationships (Abbeduto et al., 2004). Further, finding ways to decrease parenting stress would allow parents more opportunities to be involved in their child's treatment. If a parent is too stressed, even the best intervention will not be as helpful as parents will feel they do not have time to complete the practical aspects of the intervention (e.g., homework, practices, self-monitoring) and will cause more stress for the parents and child. Prior to implementing any intervention, it is essential to assess the parent's needs, level of stress, as well as the family reality to determine the best ways to support the family without increasing stress (Rao & Beidel, 2009).

Parents' relationships with professionals were considered very important. All parents reported at least one positive relationship whereby they felt supported and were an active member of their child's treatment team. Parents felt that their expertise as their child's parent was validated and valued. As such, they were more likely to be involved in their child's care. Further, parents reported less distress when their relationships with professionals were positive, even when the child did not achieve desired educational and behavioral outcomes. Poor relationships with professionals were associated with greater parent distress, poor intervention outcomes, and lack of parent involvement. Further, there was a "disconnect" between the needs cited by the parents and the need being addressed by the professionals. It has been shown that collaboration between parents and social service and educational professionals is key to maintaining positive child outcomes (Ivey, 2004). Parent-teacher alliance was found to predict family quality of life, with positive relationships leading to improvements in parental outcomes (Boehm et al., 2015).

Parents in both studies perceived services and clinical practices as being a source of stress when there was poor collaboration or communication between them and the professionals working with their family. Several factors influenced the collaboration between parents and professionals. High turnover impeded parents' willingness and ability to foster positive relationships. They reported being "fed up" of repeatedly starting over, sometimes as often as every few months. The professionals' demeanor and the way in which they interacted with parents could prevent successful collaborations. When service providers acted in an unprofessional manner (e.g., minimizing parents' knowledge of their children, speaking in clipped tones, asserting their expertise in a condescending manner), parents had greater difficulty successfully collaborating with them. As a result, the relationship was conflictual, and they expressed dissatisfaction with the services received. This is in line with previous research demonstrating that the way the professionals conducted themselves was a predictor of parental satisfaction (e.g., Crane et al., 2016; Jones et al., 2014). Parents expressed dissatisfaction when professionals would engage in "bad" practices including talking about the child in front of the child, providing the diagnosis in writing as opposed to in person, and lack of sensitivity (Jones et al., 2014). Parents' satisfaction was increased when professional manners were employed. These included being sensitive to the parents' emotions and needs; consulting with the parents as co-

experts, and demonstrating knowledge and empathy (Jones et al., 2014). These findings highlight the need for professionals to be mindful of the way in which they interact with parents and their children. Professionals should have open communication and collaboration with families, as well as knowledge of their values, needs, and cultural beliefs (Mount & Dillon, 2014; Galpin et al., 2017; DePape & Lindsay, 2015).

In Study 1, very few participants spoke of active transition planning for their adolescents. There is a clear discrepancy between existing educational and social policies that purport to facilitate the transition to adulthood and what is actually being implemented in settings (e.g., Hendricks & Wehman, 2009; Kurcharczyk et al., 2015). While some of the mothers stated that they believed a plan would be created in the future (when transitioning to adulthood), the adolescents' current objectives did not appear to be in line with future planning (e.g., vocational training, academics for those aspiring to go to postsecondary institutions). Many were unaware that such a process even existed. Parental involvement has been shown to be important for successful transition planning (e.g., Neece, 2009). Though it may be their child that is undergoing the transition, future plans also have an impact on parental well-being (Neece, 2009). As such, more proactive transition planning needs to be done and opportunities should be created to encourage and elicit parental involvement in the process.

Poor knowledge of ASD and a lack of experience working with children with ASD were significant stressors for parents. Parents perceived the professionals as being unable to meet the needs of their child due to lack of training or experience. At times, interventions were deemed to be unhelpful or failed to consider the individual needs or deficits of the child. Things became more complicated when the child had a co-occurring condition as professionals were unsure of how to address the child's multiple needs. Further, co-occurring conditions caused professionals to be caught in a mandate conflict with other organizations that address the co-occurring condition. Indeed, existing services fail to consider difficulties from a secondary diagnosis due to a lack of knowledge (Cadmun et al., 2012). Further, professionals have more difficulty in their intervention planning when there is a co-occurring diagnosis (e.g., Cadman et al., 2012). These findings highlight the need for increased professional training not only in ASD, but in co-occurring conditions. In addition, clear arrangements need to be established between the different service organizations to ensure proper care of individuals with co-occurring diagnoses.

Parents were cognizant that professionals tried to do their best despite limited resources and personnel. They acknowledged that the difficulties inherent in the system are not due to the professionals but rather, due to policies and existing protocols created by policy makers and administrators. This is in line with previous literature which has demonstrated that parents appear to be more frustrated by service level characteristics (e.g., access to care) than by practitioner level characteristics (Hodgetts et al., 2017).

Informal sources of support (e.g., other parents of children with ASD, friends of acquaintances who work in the system) appeared to be more helpful than formal sources of support (e.g., established government services). This was often because these individuals were addressing parents' specific needs, such as information about how to apply to a service. Parents reported that informal sources provided them not only with intervention on services or intervention strategies, but also validation of their shared lived experiences. This is consistent with other studies that have shown how social support can improve well-being of parents of children with ASD (e.g., Bishop et al., 2007; Bromley et al., 2004). Further, parental well-being was associated with informal sources of support and less associated with more formal sources of support (White & Hastings, 2004; Yu et al., 2018). Thus, while formal supports may be helpful

in decreasing some stressors in parenting by addressing their child's intervention needs, other parents of children with disabilities appear to be the most helpful overall. This could be because parents of other children with disabilities have a better sense of what the parents "need", as they are likely the same needs these parents had at that stage. Further, parents reported more support in the form of practical aspects of caregiving (e.g., intervention tips, information about services) as opposed to emotional support. It is possible that given the child's age, the parents have already mourned their child's disability and are more "problem-focused" in their approach. However, this was not the case for Study 2 where more parents reported struggling with mourning their child's disability. This could be due to fact that children in this study were younger. As such, the diagnosis might have been relatively new for some parents.

The findings from the present studies highlight the need for policy change in offering family-centered services as the effects of parenting stress and behavior difficulties have an impact on the family unit. For example, if a mother is experiencing distress, this can have concurrent impacts on other systems within the family unit (e.g., relationship with spouse, relationship with other children). As such, services for children with ASD should simultaneously offer services to other family members to promote the well-being of the entire family (De Paz et al., 2017). Research has demonstrated that while parents experience some aspects of family-centered care, other aspects (e.g., eliciting parental concerns, involving parents in care) are lacking (Hodgetts et al., 2013; Myers et al., 2020; Nicholas et al., 2020). Further, system constraints made it difficult to fully implement a family-centered approach. There are clear needs for improved general practices including assessing the parents' needs; enhancing parental capacities through training and intervention; ensuring positive relationships between parents and professionals; promoting active parental involvement, especially during transitional periods; and family-centered care.

Implications

The results from the studies in the present dissertation helped shed light on the lived experiences of parents with children with ASD in accessing and using specialized services. The findings demonstrated that parents' perceptions of the support received influenced their reported levels of stress. Parents' Perceptions Theory elucidates that if parents perceive support as not meeting their needs, or those of their child, they will continue to report elevated levels of stress, even if they are actively receiving services. These findings highlight the need to evaluate existing service delivery protocols to determine how to better meet the needs of these families. Further, professionals working with these families and their children need to be sensitive to parents' stress and be ready to provide support not only through direct intervention with the child, but to better support parents.

In line with the Parents' Perceptions Theory, professionals working with these families need to gain a better understanding of the needs of the family and child. Upon starting services with these families, professionals should assess the parent's needs as well as their perceptions of their child's needs. Parents need to be active partners in all decision making. Professionals should actively collaborate with parents to establish intervention goals and discuss what clinical practices would be the most helpful for the family. Such assessments should be done throughout service delivery as the needs can change based on several factors including the child age's, changes in family situation, upcoming transitional periods, and gains or regression of skill.

In addition to understanding their needs, parents reported several other areas that were sources of stress. Many parents endorsed turning to private services due to long waitlists. Others

reported needing the services but were unable to afford them. There is a clear need for increased financial support for families for respite, private services, or tangible support (e.g., materials, hiring someone to clean). Financial support may be especially beneficial to families of lower socioeconomic status who may have difficulty accessing services. Further, additional financial support such as establishing government health and service plans that cover the costs of interventions and other needs for families of children with disabilities and better or increased coverage on insurance plans may also alleviate stress from families. Finally, flexible employment opportunities that accommodate the changing needs of families may help ease stress and financial strain and allow parents to keep working should they wish to do so (Kuhlthau et al., 2014).

Across both studies, parents reported a significant lack of resources including respite, training, as well as continuing and appropriate interventions throughout the lifespan. In fact, parents reported that respite services had to be booked in advance and were rigid in terms of scheduling. Further, the frequency and availability of respite services were not enough to meet their needs. Parents cited that these services were less helpful as they were unable to receive the services when they truly needed them. To better meet the needs of these families, services should attempt to offer more respite opportunities in a more flexible manner (Cadman et al., 2012; Preece, 2014). For example, offering respite services where the parents can book based on their needs as opposed to a fixed schedule. In addition, increased coaching to help parents learn how to manage difficult behaviors and oppositional behaviors; services throughout the lifespan; and appropriate daytime activities for adults would help alleviate some of the caregiver impact experienced by these families (Galpin et al., 2017; Cadman et al., 2012; Hartley et al., 2012; Shawler & Sullivan, 2017).

Participants in Study 1 frequently cited frustrations that educational programming would only focus on specific aspects while ignoring other facets deemed important to parents (e.g., focused on dated intervention plan goals instead of more functional ones, not enough focus on academics). This highlights the importance of having families (parents and the child with ASD) as allies in intervention planning and service delivery and support (e.g., Hendricks et al., 2009; Wong et al., 2020). Transition and intervention planning have a better chance of being implemented and being effective if they include the key individuals from all settings (e.g., families as well as school and other service professionals; Iovannone et al., 2003). Further, studies demonstrated that this involvement increased the likelihood of the intervention being successful (e.g., Iovannone et al., 2003). As such, family involvement should take into consideration families' optimal level of participation based on their current reality, family stressors, and the needs of their child. Intervention plans should emphasize functional goals in the domains of social skills, leisure skills, vocational training, communication, home life, and relevant academics (Downing, 2005; Schall et al., 2006).

Rethinking existing disciplinary methods or service criterion may provide more support to parents (Johnson & Simpson, 2013). Expelling or removing youth from certain settings does not always send the message that certain behaviors are not acceptable. Indeed, parents reported that this was reinforcing their child's negative behaviors by allowing them to go home. Moreover, these strategies mean the parents must keep the child at home or find alternative arrangements for their child, thereby increasing their stress. These types of strategies also fail to address the underlying behavioral difficulty and eliminate a much needed form of respite for parents (Johnson & Simpson, 2014).

Parents in both studies reported feeling stressed and tired. Studies have demonstrated that parents of children with ASD have poorer mental and physical health (e.g., Abbeduto et al., 2004; Khanna et al., 2011). Our findings highlight the importance of family-centered interventions. From an Ecological Systems perspective, the well-being of parents is not only influenced by their caregiving impact, but also by the services that offer support to them and their children (Bronfenbrenner, 1977). As such, targeted interventions for parents should aim to improve mental and physical health outcomes (Khanna et al., 2011). Individual therapy that is offered as part of standard service delivery could help address parents' needs for emotional support. Parents of children with ASD are faced with many stressors over which they have little control. The process of changing a child's behaviors is often a long and difficult path, even with proper intervention and supports. As such, acceptance of the situation may be a more helpful way of coping (McGrew & Keyes, 2014; Rayan & Ahmad, 2017). Mindfulness Based Interventions and Acceptance and Commitment Therapy (ACT) teach parents how to accept what they cannot control, act in line with their values, pay attention to their own emotional and physical needs, and promote more mindfulness in their interactions with their child (Lunsky et al., 2017). Cognitive Behavior Therapy (CBT) techniques such as cognitive restructuring and monitoring one's thoughts and feelings have been found to enhance parental well-being (Hastings & Beck, 2004). If parents can improve these health outcomes through support services, this may have an impact on their actual and perceived abilities to parent their child. This, in turn, may lead to more positive outcomes for their child.

Given the importance of social support networks for parents, interventions should focus on creating and maintaining both formal and informal support systems for parents (McGrew & Keyes, 2014; Barker et al., 2014). Support groups, such as parent-to-parent programs, have been found to be effective in helping parents build a support network (Santelli et al., 2000). These support groups pair veteran parents with parents who have a newly diagnosed child. The more experienced parents provide a specific kind of support as they have experienced the difficulties of the new parent. The veteran parents can help teach new parents how to cope and provide them with intervention strategies (Santelli et al., 2000). Participants in both studies endorsed having significant time constraints and multiple responsibilities which left them with no additional time for anything "extra". As such, their ability to participate in such therapies may be limited. Offering these services as workshops may fit more easily in their hectic schedules (Blackledge & Hayes, 2006; Rayan & Ahmed, 2017). Further, having such interventions embedded within their existing services for their child with ASD may make it easier for them to attend (Blackledge & Hayes, 2006; Lunsky et al., 2017). Exploring other alternative modalities for treatment such as online workshops and services might increase parent participation (Lunsky et al., 2017).

At the level of the macrosystem, programs can be implemented to help provide information about ASD within society (Bronfenbrenner, 1977). Many parents reported feeling judged by others when they were with their child in the community. As a result, parents reported feeling isolated. Further, they would avoid going out with their child for fear of a behavioral outburst that would lead to the judgement of others. This not only leads to parents feeling isolated, but also to children or adolescents with limited interactions with others in the community. This leads to increased isolation for children with ASD and prevents them from having opportunities to learn essential life skills (e.g., how to buy things, behaviors in public spaces). Psychoeducation on ASD and its related symptoms could help reduce the fear of judgement of parents while helping to end stigmatization.

Future Directions

Future research should look at combining subjective measures of stress with objective measures of stress and see if they align. It would be important to determine if parents' negative perceptions of all the supports that were constructed in our interpretation directly influence their reported levels of stress on objective measures. This would help provide information as to the best measures of parenting stress. It is clear that service delivery protocols need to change as they are currently not adequately addressing the needs of families of children with ASD. Intervention studies could be helpful in evaluating if assessing and meeting the specific needs of parents helps alleviate parenting stress. Further, research exploring the experiences of the individual experiencing the service (e.g., the child with ASD) would help provide a clearer picture of the families needs. In addition, examining the expectations and perceptions of professionals would be beneficial in identifying whether they have similar difficulties as parents due to issues that are at a macrosystem level. With the knowledge from all three perspectives (child, parent, and professionals), service delivery might become more optimal and meet the needs of all parties.

The results from the present studies, as well as the existing literature on parenting stress in ASD, emphasize the need for family-centered care. There are a few studies that have examined the implementation of family-centered care for families of children with ASD (e.g., Hodgetts et al., 2013; Myers et al., 2020; Nicholas et al., 2020). These studies found that families experienced some aspects of family centered care (e.g., person-centered approach, consultation with parents) but that other aspects were missing (e.g., insufficient communication, not eliciting or listening to parents' concerns; Hodgetts et al., 2013; Myers et al., 2020; Nicholas et al., 2020). As such, further research is needed to determine how family centered care can be successfully implemented in social service and medical settings.

Strengths and Limitations

The present studies had both strengths and limitations. Both studies had some limitations which should be taken into consideration when interpreting the results. It is important to note that generalizability is not the goal of qualitative research. Rather, the purpose is to provide a rich, detailed account of the lived experiences of its participants. The participants in both studies were mostly mothers of European descent living in a large metropolitan city. As such, the results may not be generalizable to fathers, individuals in suburban settings, and individuals of other ethnic and cultural groups. Future studies should examine the views of fathers and ethnic minorities, as their experiences in accessing and using services may differ significantly from the participants in the present study. In addition, the age ranges in both studies were quite broad. Further, the study participants were recruited by convenience sampling. A complication of this type of sampling is that it is not possible to determine if those who participated in the study had different experiences than those who chose not to participate. It is possible that the individuals who wanted to participate in the study were those who experienced more challenges.

Secondly, participants were only interviewed once so theoretical sampling for Study 1 was done on subsequent interviews with new participants. This limited the ability of the researcher to follow-up on earlier statements of the participants (Charmaz, 2014). Third, interviews were conducted in French or English. Though the interviews were transcribed in their original language, the coding and identification of themes was done in English. As such, some of the nuances of the meanings in the French interviews may have been lost in translation.

Finally, a key feature of Constructivist Grounded Theory is that researchers are directly involved in the construction of the theory based on the data collected (Charmaz, 2014). That is, the researcher acknowledges and uses prior knowledge, along with the data collected, to interpret the phenomenon of study (Charmaz, 2014). As such, these studies are the interpretations of the current researchers with this group of parents, thereby limiting generalizability to other groups of parents and researchers.

The studies also had some strengths. The investigations in both studies were preliminary in nature. The author sought to obtain information about parents' experiences in accessing services. Study 1 addressed an existing gap in the literature on transitions in adolescence by understanding the perspectives of mothers with service access and use. Study 2 provided information on the experiences of parents of younger children and how their daily life might be impacted by raising a child with ASD. A strength of these studies was its sample size. Study 1 consisted of 78 mothers which is a rather large sample for a qualitative study. Study 2 consisted of 20 parents which is considered a moderate sample size for this type of study. Various strategies were used in the studies to increase the trustworthiness. All data was gathered through semi-structured open interviews, allowing to get the most information about the participants' lived experiences. Further, the data was analyzed by three researchers. This provided some rigor and objectivity to the data analysis and decreased the likelihood of researcher bias. The codes and themes were created with other researchers to ensure that they best captured the experiences being shared by the participants.

Another strength of Study 1 was in the construction of the theory. The findings from Study 1 lead to the Parents' Perceptions Theory which demonstrated that parenting stress arises not only from the lack of resources, but rather their perception of supports being unhelpful as they do not meet their needs. Specifically, even if parents received services, stressors were not improved as the parents identified that the services did not meet their child's needs. In Study 2, the Parents' Perceptions Theory was present in a sample of parents with younger children with ASD. The specific methodology of Study 1 was a significant strength. The systematic and flexible approach of Constructivist Grounded Theory helped to identify a theory that might not have been discovered through other methodologies (e.g., quantitative approaches). Further, being able to validate the Parents' Perceptions Theory in Study 2 highlighted a significant gap in understanding parenting stress for these families. Even in a population of parents of younger children with ASD who were asked significantly different questions about their experiences, the Parents' Perceptions Theory was still prominent. It demonstrated the extent to which parents' needs are not met by existing supports. These findings provide important directions for future research and potential intervention programming. They also highlight the importance of understanding parents' needs and experiences to help create a system of service delivery and access that alleviates the caregiving impact.

Role of the Researcher

The author was involved in the collection, coding, and interpretation of the data. As the author had previously worked in the social service system, several steps were implemented to ensure that the author's biases and prior knowledge did not influence the author's understanding of the data. The author worked closely with her thesis supervisor and research assistants during the coding. The coding was done by the author and four research assistants (2 for each study).

Codes were discussed and the final coding schemes were elaborated as a team. Kappa's coefficient was used to obtain an objective measure of interrater reliability.

Conclusion

The present set of studies explored the experiences of parents with services access and use. Study 1 examined service use during transitions in adolescence, specifically the transition to high school and the transition from high school to adulthood. Study 2 used the coding scheme developed in Study 1 to determine if similar themes were found in a group of parents with younger children with ASD.

In Study 1, a Constructivist Grounded Theory approach was implemented, and mothers were interviewed about their relationships with professionals, service access and use, and factors that helped or hindered the transition process. Mothers reported numerous stressors and challenges related to service access. These fell into four different categories: Parent Stressors, Professionals, Services, and Solutions. Consistent with Constructivist Ground Theory, the Parents' Perceptions Theory was constructed which demonstrated that parenting stress arises not only from a general lack of services, but also from the perceived lack of support. That is, even when parents were receiving services, they still reported stress as they perceived the services as not addressing their, or their child's, needs.

In Study 2 similar results to Study 1 were found, with parents reporting significant stressors that fell within one of three categories: Parent Stressors, Professionals, and Service. The Parents' Perceptions Theory evident in Study 2 as parents endorsed stress when they perceived supports as not meeting their needs, even if they were actively involved with services. These findings demonstrate that these difficulties do not only occur in adolescence or during periods of transition but begin earlier in the child's life. The present studies highlight that it is imperative that professionals and service providers assess a family's needs to offer supports that are helpful to the family.

Taken together, the findings from these studies provide insight on parents' experiences with service access and use for their children with ASD. These findings have implications for professionals and policy makers working with these families on how service delivery and use can be altered to better meet the needs of these families. Further research on how professionals can evaluate parents' needs and perceptions is warranted in order to identify the best policies and strategies to adopt to improve service delivery. Further, studies examining the perspectives of professionals working with individuals with ASD and their families and individuals with ASD would offer a more complete picture of how to improve service delivery at all levels.

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Appendix A

Transition Interview

1. To date, we have asked you about your experiences during your child's transition into high school or from high school to adulthood through the various questionnaires you have completed. Now, we would like to hear more about what you have to say as there might be many things we have not asked which you believe are important to share. Please tell us about your experiences accessing and using services during your child's transition.
 - a. Probes:
 - i. Did you have any difficulties obtaining information about the different services available to you and your child?
 - ii. What obstacles did you face when trying to access services?
2. When working with the professionals involved in your child's care, what practices did you find helpful and/or unhelpful? What would you do differently?
 - a. Probes:
 - i. Can you describe your relationships with the professionals working with you and your child?
 - ii. How would you describe the communication and collaboration with the professionals working with you and your child?
 - iii. Did you feel like you were an active partner in the transition?
3. Is there anything else that we have not discussed that helped or hindered your child's transition?
4. If you could make any changes about your child's transition programming or the transition outcome (if youth has transitioned into adult services), what would it be?

Appendix B
Stress and Service Interview

1. Can you describe the challenges or issues that you face on a daily basis?
 - a. Probe:
 - i. How would you describe these challenges?
 - ii. In what ways are these stressful for you?
2. How have these challenges changed over time?
3. What is the most stressful thing about being a parent of a child with special needs?
4. Was there anything that our study did not capture with regards to the challenges you face regularly?
5. What were the most helpful strategies in helping you cope with the challenges of raising a child with special needs?
6. We provided a list of coping strategies in the questionnaires you completed for the study. Were there any that were particularly relevant or helpful to you?
7. What were the challenges you faced when trying to access support services for your family?
 - a. Probes:
 - i. Can you tell me more?

Appendix C

Themes Present in Study 1

1. Parent Stressors (PS)

- a. Unmet Needs
 - i. Services for child/family
 - ii. Access to information
 - iii. Inexistent services
- b. Child-Related Stressors
 - i. Behavior problems
 - ii. Communication
 - iii. Child's well-being
 - iv. Relationship with child
 - v. Health-related issues
 - vi. Co-occurring conditions
- c. Daily Hassles
 - i. Transportation for child
 - ii. Home-related stressors
 - Other children
 - Family difficulties
 - Living situation
 - iii. Financial
 - iv. Employment
 - v. Family schedule/organization
- d. Emotional Stressors
 - i. Concerns about child's present and future
 - ii. Parent aging
 - iii. Social isolation
 - iv. Marital problems
 - v. Coping with/mourning child's disability
 - vi. Judgement/reactions of others
- e. Service-Related Stressors
 - i. Staff turnover
 - ii. Turning to private services
 - iii. Lack of services for adolescents/adults
 - iv. "Fighting" for services/Advocacy
 - v. Paperwork
 - vi. Waitlists
 - vii. Obstacles
 - Government policies
 - Costs
 - Criterion-based services/Conditional services
 - Location/time
 - viii. Timing of services
 - End prematurely
 - Begins too late

- ix. Appropriateness of services
 - Meets needs of child/family
 - Does not meet needs of child/family
- x. Continuity of services
- xi. No emergency services or placements
- f. Emotional Reactions
 - i. Anger
 - ii. Guilt
 - iii. Sadness
 - iv. Feeling invalidated/not heard
 - v. Frustration
 - vi. Happiness
 - vii. Anxiety/Worry
- g. Extra Roles
 - i. Supplemental service provider
 - ii. Care coordinator
 - iii. Advocate
- h. Buffers of Stress
 - i. Other parents/services professionals uninvolved with the child
 - Provide information about services/intervention
 - Provide strategies/tips

2. Services (S)

- a. Inconsistent Information Transmission
 - i. Information not transmitted
 - ii. Information transmitted too late
- b. Large caseloads for professionals
- c. Mandate Conflicts Between Services/Departments
- d. Funding
 - i. Lack of adequate funds for services/programs
 - ii. Poor distribution of funds

3. Professionals (P)

- a. Experience, Information, Knowledge
 - i. Lack of Experience/Expertise
 - ii. Appropriate Experience/Expertise
 - iii. Poor knowledge of services
 - iv. Adequate knowledge of services
- b. Communication
 - i. Interpersonal skills
 - Good interpersonal skills
 - Poor interpersonal skills
 - ii. Providing and sharing information
 - Information is transmitted from professional to parent
 - Information is not transmitted from professional to parent

- c. Motivation
- d. Collaboration
 - iii. Following-up
 - Professionals follow-up with parent
 - Professionals do not follow-up with parent
 - iv. Parental involvement
 - Parent involved
 - Parent not involved
 - v. Multidisciplinary
 - vi. Relationship quality
 - Parent endorses positive relationship with professionals
 - Parent endorses a negative relationship with professionals
- e. Proactive Intervention
 - vii. Transition planning

4. Parent Solutions (PSol)

- a. Relationship between parents and professionals
 - i. Increased communication
 - ii. Increased collaboration
- b. Services
 - i. Continuity of services
 - ii. Increased funding
 - iii. Increased services
 - iv. Parent workshops and trainings
 - v. Easier access to information
 - vi. Appropriate and proactive services and interventions

Appendix D Themes Present in Study 2

1. Parent Stressors (PS)

- a. Unmet Needs
 - i. Services for child/family
 - ii. Access to information
- b. Child-Related Stressors
 - i. Behavior problems
 - ii. Communication
 - iii. Health-related issues
- c. Daily Hassles
 - i. Transportation for child
 - ii. Home-related stressors
 - Other children
 - iii. Financial
 - iv. Employment
 - v. Family schedule/organization
- d. Emotional Stressors
 - i. Concerns about child's present and future
 - ii. Parent aging
 - iii. Social isolation
 - iv. Marital problems
 - v. Coping with/mourning child's disability
 - vi. Judgement/reactions of others
- e. Service-Related Stressors
 - i. Staff turnover
 - ii. Turning to private services
 - iii. Lack of services for child
 - iv. "Fighting" for services/Advocacy
 - v. Paperwork
 - vi. Waitlists
 - vii. Obstacles
 - Costs
 - Criterion-based services/Conditional services
 - Location/time
 - viii. Timing of services
 - End prematurely
 - Begins too late
 - ix. Appropriateness of services
 - Meets needs of child/family
 - Does not meet needs of child/family
- f. Emotional Reactions
 - i. Anger
 - ii. Guilt
 - iii. Sadness

- iv. Feeling invalidated/not heard
- v. Frustration
- vi. Happiness
- vii. Anxiety/Worry
- g. Extra Roles
 - i. Supplemental service provider
 - ii. Care coordinator
- h. Buffers of Stress
 - i. Other parents/services professionals uninvolved with the child
 - Provide information about services/intervention
 - Provide strategies/tips

2. Services (S)

- a. Large caseloads for professionals
- b. Funding
 - i. Lack of adequate funds for services/programs
 - ii. Poor distribution of funds

3. Professionals (P)

- a. Experience, Information, Knowledge
 - i. Lack of Experience/Expertise
 - ii. Appropriate Experience/Expertise
 - iii. Poor knowledge of services
- b. Communication
 - i. Providing and sharing information
 - Information is transmitted from professional to parent
 - Information is not transmitted from professional to parent
- c. Motivation
- d. Collaboration
 - ii. Following-up
 - Professionals follow-up with parent
 - Professionals do not follow-up with parent
 - iii. Parental involvement
 - Parent involved
 - Parent not involved
 - iv. Relationship quality
 - Parent endorses positive relationship with professionals
 - Parent endorses a negative relationship with professionals