PARENTAL PERSPECTIVES OF STRESS AND SUPPORTS ACROSS THE LIFE CYCLE OF INDIVIDUALS WITH MODERATE TO SEVERE AUTISM

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A thesis submitted to the faculty at the University of North Carolina at Chapel Hill in partial fulfillment of the requirements for the degree of Master of Arts in the Early Childhood, Special Education, and Literacy Program in the School of Education.

Chapel Hill
2014

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ABSTRACT

Xueyan Yang: Parental Perspectives of Stress and Supports Across the Life Cycle of Individuals with Moderate to Severe Autism
(Under the direction of Harriet Able)

Parents of individuals with autism spectrum disorders experience high levels of stress. Nonetheless, they possess resilient qualities and rely on formal and informal supports to cope with challenges. The aim of this study was to explore the stressors and supports parents of individuals with moderate to severe autism experience across the life cycle stages of their child, from early childhood to adulthood. Semi-structured interviews were conducted with nine parents from eight families across different stages, who identified the challenges and supports they experienced and described how these have changed over time. Analysis of the data revealed themes of stress and support specific to individual stages and overlapping across stages. Implications for practice include educating teachers and service providers about autism, provision of family-centered services, and addressing finance and systemic concerns.
To the parents in this study – you have been, and still are,

an inspiration in more ways than you know.
ACKNOWLEDGEMENTS

My heartfelt thanks to my advisor, for your invaluable advice, patience, and encouragement during this whole process, and to my committee, for your support and grace. I would like to express my sincere thanks to the persons and organizations for their generous help during my recruitment process. Thank you Ranjitha Ananthan and Darshan Patel for assisting with the transcribing. Thank you Niaisha Johnston for your help with transcribing and endless hours of coding. A special thanks to my family and friends who have prayed along with me and supported me in various big and little ways throughout this entire journey.
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CHAPTER 1: INTRODUCTION

Prevalence rates of autism have been on the rise. The Centers for Disease Control (CDC) reported prevalence rates to be 1 in 68 (CDC, 2014). A more recent report estimated the figure to be 1 in 50 (Blumberg et al., 2013). This increase in prevalence rates suggests the possibility that more families have the task of caring for a child with autism and underscores the need to understand the stressors associated with caregiving as well as the supports that are present and needed to facilitate the caregiving process.

Research has generally indicated that parents of children with autism face increased stress and lower psychological well-being compared to parents of typically developing children (Montes & Halterman, 2007; Rao & Biedel, 2009) and to parents of children with other developmental delays or disabilities (Estes et al., 2013; Sanders & Morgan, 1997). A recent meta-analysis conducted by Hayes and Watson (2012) found significantly larger effect sizes for parenting stress in families of children with autism compared to families of typically developing children and families of children with other disabilities.

In spite of the evidence indicating higher levels of parenting stress, existing literature suggests that families also have supportive factors helping them cope with their challenges (e.g., Bayat, 2007). This includes intrinsic factors like resiliency, where families encountering adversity discover or develop strengths that enable them to persevere and grow through the experience. Strategies that such families may engage in are problem-solving strategies and reframing (DeMarle & le Roux, 2001). Supports from external sources may include informal supports, such as other family members and friends, and formal supports, such as schools and professionals working with the child and family, or systems in place providing services to the family (e.g., Meadan, Halle, & Ebata, 2010; Siman-Tov & Kaniel, 2011).
However, most research on the stressors and supports of families of individuals with autism has been centered around the middle childhood ages. Fewer studies examine the specific stressors experienced and the supports required at the very early childhood stage of pre-diagnosis and initial post-diagnosis (e.g., Davis & Carter, 2008), as well as at the later stages of the life cycle, as the child becomes an adult (e.g., Orsmond, Lin, & Seltzer, 2007; Smith et al., 2010). Furthermore, those studies focusing on older individuals with autism tend to group adolescents and adults together rather than distinguishing between the two. For example, Smith, Greenberg, and Seltzer (2012) studied the daily experiences reported by mothers of adolescents and adults with autism spectrum disorders (ASD). The mothers in their study were of individuals with ASD whose ages ranged from 17 to 53 years, with the mean age being 24.78 years ($sd = 7.28$). Similarly, in another study by Lin, Orsmond, Coster, and Cohn (2011) examining the impact of social support and coping strategies on family adaptation and maternal well-being focused on mothers of adolescents and adults with ASD with an age range of 10 to 31 years. No distinction was made between adolescents and adults in either study.

In addition, few studies have examined how these challenges and supports caregivers experience change across the child’s life cycle. As Meadan et al. (2010) note, there is insufficient understanding on the stressors and supports of families of children with autism over time and at specific transition points. For example, a longitudinal qualitative study by Gray (2002) documented the psychosocial adaptation of parents of children with autism at two time points, the first when the children were aged 4 to 19 years, and the second about 8 to 10 years later, when children were between 13 and 27. While this study provided an overview of how parents’ experiences changed about a decade later, the age range of children at both time points overlaps between early and middle childhood for the first, and between adolescence and adulthood in the second. In fact, the children’s age range at the first time
point overlaps with that of those in the second time point. Hence this study only captured the change in parents’ experiences over time, but not necessarily changes specific to the child’s life cycle stage.

A recent paper by Neely, Amatea, Echevarria-Doan, and Tannen (2012) discussed the issues faced by families of individuals with ASD from the early school years to adulthood. However, this paper drew on examples based on the authors’ personal and professional experiences rather than a systematic examination of families of individuals with ASD across the life cycle stages. These limitations point to the need for a more systematic examination of parents’ caregiving experiences across the life cycle stages in order to provide a better understanding of how specific challenges and supports differ for parents across the child’s life cycle stages.

Parents are usually the child’s main source of support. In order to support the child with autism, assistance needs to be provided to the parents who are usually their primary caregivers (Bailey et al., 2006). As the child progresses from early childhood to adulthood, he/she goes through several stages of life. Each stage of the life cycle is accompanied by events and experiences that are normative and characteristic of that period of time. These events may be accompanied by stressors and supports unique to each period. Furthermore, parents often remain the primary caregivers of their child with autism even when the child enters adulthood. However, the availability and accessibility of supports are often substantially reduced when the individual with autism enters adulthood (Gray, 2002). Hence, there is a need to understand how parents’ experiences of stress and support change as the child matures in order to better support them.

In view of the limitations in the research mentioned above, this study aimed to contribute to current understanding of parenting experiences across the child’s life cycle stages by first classifying participants into the following groups: early childhood (pre-
diagnosis and initial post-diagnosis; ~0-7 years), middle childhood (~8-13 years), adolescence (~14-19 years), and adulthood (post-secondary; ~20 and above). By examining parental experiences in these four stages, I hoped to identify the intricacies of the challenges and supports unique to each stage.

In line with the aim to examine parents’ experience across the life cycle, this study focused on parents of individuals with moderate to severe autism for two reasons. First, individuals with moderate to severe autism are more likely to receive a diagnosis in early childhood, and will therefore be more represented in the early childhood life cycle stage. In contrast, those with high functioning autism may be diagnosed during middle childhood or adolescence. Second, the experiences of parents of individuals with moderate to severe autism and the issues they face may differ drastically from those with milder symptoms. Hence, in order to present a more accurate portrayal of parenting experiences, this study focused on parents of individuals with moderate to severe autism. As Piotrkowski (1979) highlighted in his seminal study on the impact of work on the family, “the sample is chosen for its relevance in revealing what is under consideration. Inevitable sampling bias is treated as a condition of the discovered relationships—it does not invalidate them” (p. 292). Limiting the sample population provided an opportunity to examine in greater depth the specific issues these parents face.

This study used qualitative methodology allowing the researcher to capture the complexities and nuances of the personal stories of parents’ personal stories, which may be otherwise lost in quantitative methodologies. Personal stories provide a powerful means of describing the parenting experience as it allows the researcher a glimpse into their world. As Pugach (2001) notes, “the power of individual stories of persons with disabilities – and the struggles they have endured – undergirds the advocacy that continues to serve the field of special education so well in achieving the current level of rights those with disabilities enjoy”
Providing a platform for these individual stories to be told and heard gives voice to the challenges parents face as well as the supports and successes they experience at the respective stages of the child’s life cycle, thereby providing useful implications with regards to supporting families of children with autism.

Statement of Purpose

The overall purpose of this study was to understand the challenges and supports parents of children with moderate to severe autism encounter across different stages of the child’s life cycle. More specifically, this study sought to elicit the parent’s experiences of stressors and supports unique to each stage and how they change across the life cycle stages. Hence the two research questions of this study were:

1. What are the stressors and supports encountered by parents at each life cycle stage of the individual with moderate to severe autism?
2. How do these stressors and supports change or remain constant across the life cycle stages?

It is hoped that a better understanding of the parenting challenges and supports across the child’s life cycle will contribute to existing knowledge on parenting experiences and also inform practice and policy in terms of providing better assistance to parents, especially at the early and later stages of the child’s life cycle.
CHAPTER 2: LITERATURE REVIEW

This chapter will begin by discussing the conceptual framework guiding the study to examine the impact of autism on the life cycle stages of the individual with autism and its subsequent effects on the family. The stressors and indicators of resilience and supports associated with each stage of the life cycle will then be presented, followed by a summary of the stressors and supports present across all stages.

The Impact of Autism on the Life Cycle

This paper draws its conceptual understanding of the life cycle stages from Carter and McGoldrick’s (2005) family life cycle framework, which will be supplemented by Rolland’s (2005) time phases of chronic illness to provide a better understanding of the life cycle stages of children and the impact on families of children with disabilities. Both of these view the child within the context of his or her family, providing a better understanding of parent’s experiences in supporting the individual with autism.

Carter and McGoldrick (2005) viewed the typical family as a system undergoing transitions through time. Relationships among family members shift as they progress along the family life cycle and the roles of each member in relation to each other are continually redefined. For instance, parents of young children are the primary caregivers and usually take on the role of the decision-maker for their young child. However, as the child matures, he/she is given more independence and greater autonomy in decision-making until he/she becomes an adult. In the later stages of the family life cycle, when the parents become older, the caregiver role is changed and the child takes on more caregiving responsibilities for his/her parents. The family life cycle by Carter and McGoldrick (2005) outlines six stages that a typical family undergoes: leaving home, the new married couple, families with young...
children, families with adolescents, launching children and moving on, and families in later life. The latter four are of interest to this study.

In a typical family life cycle, the two individuals leave their parents’ homes as single young adults and form their own marital system as a married couple. With the birth of their child, they enter the “families with young children” stage where the couple takes on childrearing responsibilities. These responsibilities shift as they enter the “families with adolescents” stage. The adolescent is given more independence and the parents may have to take on caregiving responsibilities for their parents (grandparents). “Launching children and moving on” is the stage consisting of “exits from and entries into the family system” (Carter & McGoldrick, 2005, p. 2). This includes the grown child moving out and living independently (exit), or marrying (entry of spouse and in-laws) and having children of his or her own (entry of grandchildren). It also includes the period when the parents may have to deal with disabilities or death of their own parents (grandparents). “Families in later life” refer to the stage when the parents face the issues of their own aging and the loss of spouse, siblings, and other peers.

In families of children with autism, however, the last four stages follow a trajectory different from that of families of typically developing children. Here, the major phases of families with chronic illnesses and their impact on the family described by Rolland (2005) may be applied to the life cycle of families of children with autism. The three major phases families of individuals with chronic illnesses undergo are crisis, chronic, and terminal (Rolland, 2005). In families of children with autism, the first two phases are particularly relevant and will be explained in the following paragraphs.

For families of children with autism, the “families with young children” stage is often when the child receives his or her diagnosis of autism. (Children with higher functioning autism may, however, receive a diagnosis in middle childhood or adolescence.) This stage
mirrors the crisis phase described by Rolland (2005) in his explanation of the major phases of chronic illnesses. This stage consists of the period before diagnosis and the immediate period following diagnosis. In the former period, parents may have unconfirmed suspicions that something is ‘wrong’, while in the latter period, parents may be grieving for the loss of the expectations and hopes they originally had for the child and making adjustments in their expectations and accommodations in their daily lives.

As the child progresses into mid-childhood, and adolescent stages, the family enters what Rolland (2005) terms as chronic or “long haul” phase. This phase can also be extended into the adulthood stage of the life cycle framework. Across these stages, families and individuals with autism continually adapt and make adjustments with transitions that accompany the individual with autism. This includes transitioning from middle to high school, and to post-secondary education or employment. During this time, other family members (e.g., siblings, grandparents) will also be experiencing transitions of their own depending on their life cycle stage, possibly affecting the interaction between the roles that each family member takes on. An older typically developing sibling who leaves for his freshman year at college will not be able to provide as much hands-on support to the family and individual with ASD as when he was in high school. A grandparent who could take care of the preschooler with autism may be physically less able to do so when that preschooler becomes an adolescent. Hence this extended chronic phase consists of the day-to-day living and the coping with the changes accompanying the development of the family and the individual.

In many families of individuals with autism, the stage of ‘launching children and moving on’ may be either absent or different. In typical families, this stage encompasses transitions of individual family members from and into the family system (Carter & McGoldrick, 2005). Children are usually grown and may exit from the family system to form
their own families. Entries, therefore, may include the introduction of in-laws and grandchildren. Exits could also include the parents’ aging issues leading to losses in mobility or other forms of disability, or the death of the parents’ parents (grandparents). In families of individuals with ASD however, children may never be ‘launched’ as many still live with their parents for their parents’ whole lives (Howlin, 2003; Seltzer, Shattuck, Abbeduto, & Greenberg, 2004).

Hence the stages of the family life cycle may look different for these families as their stages tend to be defined by the particular child’s developmental trajectory. Therefore, the experiences of families at the different life cycle stages may look more like this: families at early childhood (pre-diagnosis and initial post-diagnosis period, ~0-7 years), families at middle childhood (~8-13 years), families at adolescence (~14-19 years), and families at adulthood (post-secondary; ~20 and above) with autism. The following sections will discuss the major stressors and supports reported in the literature unique to each life cycle stage and conclude with an overview of stressors and supports that are present throughout the life cycle stages.

**Stressors and Supports in the Early Childhood Stage (Approximately Ages 0 to 7)**

Few studies have examined the specific stressors and supports that are typical of the pre-diagnosis and initial post-diagnosis period. These tend to center around the issues of pre-diagnosis suspicions, initial post-diagnosis reactions, and the supports addressing immediate concerns. The following section will present the stressors and supports found in the literature to be most salient at this stage.

**Pre-diagnosis suspicions and uncertainty.** In the pre-diagnosis phase, families may have had suspicions of a delay but not the formal diagnosis. Hence, this period of uncertainty and of not knowing what exactly is ‘wrong’ may be frustrating for parents (Neely et al., 2012; Sperry, Whaley, Shaw, & Brame, 1999). Uncertainty can be very stressful for parents
when they do not know what the problem is and therefore are not sure of how they can address it (Rolland 2005). In addition, parents may encounter issues such as pediatricians who are dismissive of their fears, or receiving a wrong diagnosis. The latter delays the family’s prospects of receiving appropriate intervention (Neely et al., 2012).

**Mourning process.** Receiving the formal diagnosis alleviates the stress of uncertainty. However, it is a devastating experience nonetheless. Parents of newly diagnosed children with autism undergo a grieving process for the child, as well as the loss of the hopes and dreams they originally had for their child (DeMarle & le Roux, 2001; Neely et al., 2012). As DeMarle and le Roux (2001) noted, grieving “can occur regardless of the type or severity of the child’s disability, as from the parents’ perspective, there are no mild disabilities in their children” (p. 32).

**Child characteristics.** Two studies examining parents’ stress and supports during the period of early childhood have focused on the relationship between child characteristics and parental psychological distress or stress (Davis & Carter, 2008; Estes et al., 2013). For instance, Estes et al. (2013) compared the effects of child characteristics (diagnostic status, problem behavior and daily living skills) on maternal stress and psychological distress among three groups of mothers: mothers of children with ASD, children with developmental delay (DD), or typically developing children (TD). Mothers of toddlers with ASD reported higher parenting stress, which was associated with child problem behavior.

Davis and Carter (2008) examined stress in parents of newly diagnosed children with autism and found that a third of parents reported stress scores that were in the clinically significant range, and a quarter reported depression symptoms that were clinically significant. In addition, there was a tendency for mothers in their study to report more negative outcomes although the differences were not significant. Also, mothers and fathers were affected by different aspects of the child’s behaviors. Mothers were more affected by the child’s self-
regulatory skills while fathers’ stress was more associated with externalizing behaviors. This suggests the need to examine the different roles each parent or family member plays to understand how the stressors they experience affect them. In addition, as the roles that each family member plays changes throughout the life cycle, the impact of the same stressor may change as well. Hence it is important to understand the dynamic interplay between stressors and supports and family roles within the family system.

**Parent knowledge and expectations.** Parents’ understanding of the typical developmental milestones may contribute to their stress levels. An interesting finding in the Davis and Carter (2008) study was that cognitive and verbal functioning of the child was not associated with parent stress. The authors suggest that parents of very young children may not have had clear expectations regarding age-appropriate development and may not yet view delays in these areas as stressful.

Parents who have acquired knowledge about the child’s condition and found ways to adjust may also be more adept at coping with the challenges of caring for their child with autism. For example, in Estes et al.’s (2013) study, lower daily living skills of the toddler was not associated with parent stress. The authors postulate that this is because parents had acquired knowledge and coping strategies to handle the limited daily living skills of their child.

**Supportive factors.** Given that the stressors in early childhood were associated with early identification and diagnosis, reactions to diagnosis, child characteristics and parent understanding of autism, supports found to be most helpful addressed these issues. There has been little research on supportive factors at this early stage. Supports families of newly diagnosed children were in need of or have found useful were summarized in a focus group study conducted with parents and service providers for young children (24-30 months) with ASD (Sperry et al., 1999). The areas of concern highlighted by parents included family
support, early identification, finance, training, and gaining access to appropriate services. Key supportive factors may be of an informational, instrumental, and emotional nature (Dunst, Trivette, & Cross, 1986). Informational supports include providing parents with understanding of what autism is and educating them on how they can help their child. Instrumental supports refer to practical support such as connecting parents with services and service providers. Emotional support typically comes from the social support of family and friends.

**Policy and its impact on formal supports.** Even in this early stage, there are changes at the policy level that affect the nature of formal supports parents may receive. In the United States, external support for the family changes as the child matures. Under the Individuals with Disabilities Education Improvement Act of 2004 (IDEIA, 2004), Part C provisions for children with disabilities aged 0 through 3 include the Individualized Family Service Plan (IFSP), which is family-oriented. Families receiving services here may find more family-centered practices both in schools and in interventions.

However, as the child matures, the provisions in Part B become more education-focused, and the IFSP changes to an Individualized Education Plan (IEP). This means that the types of support families have access to changes as the child matures. In addition, the decreased focus on family at such a young age (4 years) may be a concern for parents, especially as they transition to the middle childhood stage, discussed in the next section.

**Stressors and Supports in the Middle Childhood Stage (Approximately Ages 8 to 13)**

At this stage, families tend to have some level of acceptance of the child’s diagnosis leading to family adjustment and adaptation. As the child develops, certain stressors may include the child’s behavior problems and learning how to adapt to the child’s needs. In addition, family members need to adjust their own expectations and hopes for the child with ASD. The child also begins to go through rapid physiological development requiring parents
to address and adapt to the changes that occur. Events external to the family system that define this period are the multiple school transitions, where the child may (or may not) experience the normative changes from elementary to middle school.

**Child-related stressors.** Child-related factors that have been consistently highlighted are challenging behaviors and severity of symptoms, which have been found to correlate with stress and psychological distress (Bekhet, Johnshon, & Zauszniewski, 2012). For example, Benson and Karlof (2009) examined the impact of stress proliferation on depression in parents of children with ASD and found a positive correlation between symptom and behavior severity and parent depression that was mediated by parent anger and stress proliferation. This is consistent with findings from older studies. For instance, Konstantareas and Hoomatidis (1989) examined the relationship between symptom severity, and child and family characteristics on self-reported stress and found that parental stress was associated with cognitive delays, limited verbal communication skills, social impairments, and symptomatic or self-abusive behaviors.

**Parent-related stressors.** Demographic factors also can contribute to parental stress. Specific demographic factors that impact stress include having a greater number of children with disabilities (Orsmond et al., 2007) and older maternal age (Duarte, Bordin, Yazigi, & Mooney, 2005). Orsmond et al. (2007) compared mothers who had a child with autism and at least another child with autism or another disability, to mothers who had a child with autism but whose other children did not have disabilities. They found that mothers with multiple children with disabilities had higher levels of depressive symptoms and anxiety and lower family adaptability and cohesion. In a cross-sectional study examining stress in mothers of children (aged 3 to 12) with autism, Duarte et al. (2005) found that older mothers had higher stress levels. In their study, however, older mothers also tended to be working outside the
home, which could account for their higher stress levels. These mothers may have to manage both professional and home responsibilities with conflict between the two spheres.

**External stressors.** External factors could include issues such as having access to services, social support from family, and at a more general level, societal awareness and understanding of autism. Services for the child and family are typically provided through the schools. Woodgate, Ateah, and Secco (2008) examined the impact of having a child with autism on parenting roles and the actual experiences of parents within the world they lived in. Parents in their study highlighted that those factors (unsupportive or inaccessible services, disconnectedness from family, exclusion from ‘normal’ way of life, and lack of societal understanding of autism and caring for a child with autism) resulted in a sense of isolation.

This was supported by a qualitative study conducted by DeGrace (2004), which described the daily life experiences of five families of children with autism aged 9 to 10. These families reported that their family life centered around autism and was defined by the child with autism. Most of the time was also spent trying to occupy and pacify the child with autism. They also reported a sense of being robbed of ‘typical family experiences and having dreams for the future. The moments of feeling like a family were fleeting and tended to occur in the absence of challenging behaviors.

**Supportive family characteristics.** Parents who had accepted their child’s condition, had higher parental self-efficacy, strong sense of coherence and more optimistic outlook on life were found to have better outcomes. These outcomes included improved health, fewer depressive symptoms, better marital quality, life satisfaction and well-being (Bekhet et al., 2012). Other indicators of resilience in families were having more affirming family communication, family cohesion. Supportive factors include having capable siblings who could share some responsibilities of caregiving or family functioning (Greef & van der Walt, 2010).
**Higher income.** Although having a higher income is likely a supportive factor across all stages of the family life cycle, it may be especially beneficial during this stage, when quality services and supports are more readily available. Lee et al. (2009) studied the health-related quality of life in parents of children with HFA. Although the relationship between income and mental and physical quality of life became non-significant when psychosocial factors, stress in particular, were included, the authors suggested that higher income provides parents with greater access to services and supports allowing them temporary relief from caregiving responsibilities. In the study by Orsmond et al., (2007), a higher income was associated with lower depressive symptoms regardless of the number of children with disabilities. During this period of development, having the means to access quality services and supports can be critical. Financial resources can assist in providing respite from parenting stress as well as building up family strengths to support both family and child.

**Coping strategies.** Several coping strategies have been noted in studies of families at the middle childhood stage. These include information-seeking, establishing routines (Greef & van der Walt, 2010), having an internal locus of control (Siman-Tov & Kaniel, 2011), and positive cognitive appraisal (Bekhet et al., 2012). These help parents adjust their perspective and understanding on how they can support their child with autism.

In addition, advocacy was noted in Woodgate et al.’s (2008) study as one of the skills parents had developed in order to attain appropriate services and supports for their child. These parents also highlighted the importance of educating those around them about autism and their child. This could be particularly relevant during middle childhood because the child is likely to encounter more adults and children than he previously did in the preschool years. Hence, educating staff and classmates about autism and the child’s specific characteristics may increase their awareness of autism and of the child with autism, which may foster more understanding attitudes.
Family involvement in educational processes. In their meta-analysis of studies examining parent stress, Hayes and Watson’s (2012) highlight that since the literature has established that parenting stress is higher in families of individuals with autism than those without, there is a need for future studies to examine the underlying mechanisms for the stress. The present study hopes to address this need through exploring parents’ description of their parenting stressors and supports. Suggested lines of inquiry by Hayes and Watson (2012) include the characteristics of the disability, as well as the availability of supports from professionals, community, and family members. Although few studies have been found examining the direct impact of the school on parent stress, supportive factors such as family involvement and communication have been associated with improved parent satisfaction. In their review of the literature examining strategies facilitating the inclusive education process for children with ASD, Gavalda and Tan (2012) note that family involvement and communication is a critical part of special education as it improves student outcomes as well as parent satisfaction with the educational services. Hence it is important to understand the impact of schools and service providers on parents’ experience.

Studies examining families in the middle childhood stage indicate that stressors include child and parent characteristics as well as external factors such as service accessibility and societal lack of understanding, while supports examined included supportive family characteristics, higher household income, use of coping strategies, as well as family involvement in the educational process. As the child proceeds beyond middle childhood, the concerns of parents and supports required are likely to change due to the changing needs of the child and family.

Stressors and Supports in the Adolescence (Approximately Ages 14 to 19) and Adulthood Stage (Ages 20 and Above)

The adolescence and adulthood stages will be discussed together as most studies do not distinguish between the two. The adolescent/adulthood stage consists of several
transitions and critical events. In particular, as the child transitions out of high school, the amount of formal supports is significantly reduced. In addition, while many parents remain the primary caregiver throughout the life course, they may also face challenges related to their own aging. Since autism is usually a lifelong disorder, caregiving for the child extends into his or her adult life. As Patterson and Blum (1996) noted in their literature review of risk and protective factors in children and youths with disabilities, chronic conditions tend to assert demands that “have a way of taking over the family life” (p. 694), especially in terms of time, finances, and physical and emotional energy. This could create a strain on the family in the long run if supports are not provided at the appropriate stages to facilitate family adaptation and regulate family processes.

**Adolescent/adult-related stressors.** Challenging behaviors of individuals with ASD possess may continue into adulthood. For instance, in a longitudinal study by Gray (2002), families of individuals with autism reported high psychological distress but lesser emotional distress 8-10 years after their initial interview. However, those whose children were aggressive or severely obsessive still reported high levels of distress. Parents, mothers in particular, may experience poorer physical and emotional health status (e.g., fatigue, headache, increased stress and depressive symptoms) compared to parents of adults without disabilities (Smith, Greenberg, & Mailick, 2012). Smith, Greenberg, and Mailick (2012) also noted that the heterogeneity of ASD could prevent parents from developing clear expectations for the child and the future. This uncertainty regarding the young adult’s future could increase anxiety and stress in parents (Patterson & Blum, 1996).

**Parental concerns.** At this stage in the life cycle, parents becoming increasingly concerned about their child’s future. Parents in Gray’s (2002) study reported increased anxiety over their child’s future in terms of lifestyle, residential placement, and, for those whose children had aggressive tendencies, violent behavior. Such concerns have been
validated by research on outcomes of adults with ASD. Seltzer et al. (2004) noted in their literature review that although a small sub-group of individuals had favorable outcomes such as being married, independent living, having a social network and competitive work employment, majority do not achieve these normative outcomes and have sustained social impairments. Long-term normative outcomes do not typically occur even for individuals with higher functioning autism. Howlin (2003) examined outcomes in 76 adults with high functioning autism and Asperger’s syndrome and found that majority of them still lived with their parents. Of those who were living independently, most still required some form of support from family or social services. In addition, just over half of the 66 who were not in college had some form of employment. However, only four had well-paid, permanent employment. The rest were in sheltered or family firms, or had low-wage, short-term positions.

Interestingly, few parents mention concerns about their own aging-related issues. This may be embedded in their worry for the child’s future, when they are not around to support their child any longer. Alternatively, it is possible that parents who have age-related challenges may not have participated in these studies. White, McMorris, Weiss, and Lunsky (2012) conducted a qualitative online survey on the crisis experiences of parents of children with ASD across the lifespan. They found that parents of adults were especially concerned about the future, especially with the loss of both parents and when children age-out of current services.

**Limited services and opportunities for independence.** The literature review conducted by Smith, Greenberg, and Mailick (2012) examining outcomes for adolescents and adults with ASD found that common issues include the loss of services and insurance coverage, limited opportunities for independence, and a lack of daytime services and employment (which was worse for individuals without intellectual disabilities). Seltzer et al.
(2004) also noted that extensive accommodations might be required in providing care. Searching for programs and services that can support the adult with autism may prove to be a challenge as services for adults tend to be few and the quality of existing services may not be high (Gray, 2002).

**Impact of policies.** In addition, policies mandating services for children with disabilities do not usually extend into adulthood. In the United States, Part B of the IDEIA ends when the child reaches 21. This means that families who previously had formal supports in the form of school intervention and therapy, now have to search for other sources of intervention and therapies as the child exits out of school and out of the coverage of Part B of IDEIA.

An option available to the individual with autism is the Vocational Rehabilitation System (VRS). Administered by the U.S. Department of Education, the VRS helps individuals with disabilities achieve positive employment outcomes by providing individualized services such as vocational rehabilitation counseling, vocational training, transportation, supported employment, and self-employment services. These services will end when the individual has been considered successfully rehabilitated (i.e., maintenance of employment for at least 90 days).

Evidence for the benefits of supported employment was found in a study by Garcia-Villamisar and Hughes (2007) comparing the outcomes of adults with autism in a 30-month supported employment program to those on a waiting list. At the end of the program, adults who had participated in the program had improved scores on measures of executive functioning compared to the control group who demonstrated no change. Additionally, a study by Lawer, Brusilovskiy, Salzer, and Mandell (2009) compared the experience of adults with ASD relative to other adults receiving vocational rehabilitation services using a national dataset of adults aged 18 to 65 who whose cases were closed in 2005. They found that,
excluding adults with mental retardation, more than half of adults with ASD who were receiving services were competitively employed compared to adults with specific learning disabilities and other disabilities. This, coupled with findings from Garcia-Villamisar and Hughes’s (2007) study, demonstrates the value of the VRS as a formal support for the individual with autism, and in turn, the family.

A limitation of the VRS is that only individuals with disabilities who are deemed to be able to benefit from the VRS are eligible. Individuals with disabilities considered too severe to benefit from the services are not eligible. Individuals with autism who have more significant and complex impairments may be ineligible for these services. In the Lawer et al. (2009) study, individuals with ASD, compared to those with other disabilities, were more likely to be denied access to VR services because their disability was deemed too severe for services to be beneficial. As noted in Gray’s (2002) study, the limited or lack of services available to adults with autism is a primary source of concern for their parents. This highlights the need for policies and programs similar to the VRS in providing some form of assistance for adults with autism who do not meet the eligibility criteria for the VRS.

**Informal social support.** The key social supports at this stage appear to be the informal forms of social support, such as spousal, family and friends. Smith, Greenberg, and Seltzer (2012) found that for parents of adolescents and adults with autism, having a larger social support network, less negative support, and being married were key predictors of maternal well-being. In addition, they found that social support appeared to be a more salient predictor than child behavior problems at this stage. This could be because by this time, parents may have strategies to cope with challenging behaviors. In addition, as the child enters adulthood, the availability and quality of formal supports declines sharply. Hence informal social supports become even more critical for these families.
The qualitative study by Neely et al. (2012) suggests that the social and economic stresses that these families experience persist as the child matures to adulthood and beyond. Additionally, studies examining life cycles of families with an individual with other disabilities suggest that caregivers of adolescents or older adults with disabilities received less formal support than those of children with disabilities and may face more or different stressors (DeMarle & le Roux, 2001). This underscores the need to understand the impact of autism on families during this later stage of the life cycle, and to enhance their ability to receive formal supports and sustain informal social supports.

General Family Stressors across the Life Cycle

As mentioned earlier, families of children with autism have relatively higher levels of stress and depression and lower psychological well-being. Some stressors may be common across all stages of the life cycle. For instance, challenging behaviors have been noted as a stressor for parents across all stages of the child’s life cycle. This is especially true if the problem behavior persists in adulthood (Gray, 2002).

Risk factors in Patterson and Blum’s (1996) literature review that are likely to impact families of individuals with autism include the degree of invisibility of the disability, uncertain prognosis, and chronicity of the condition. Invisible conditions were found to be more stressful for the child and family. This may be especially true for families of children with higher functioning autism. Services may be more difficult to obtain for children whose disability is not as evident, particularly if they are performing well academically. This can be frustrating for parents who desire more services for their child but are unable to access those services because their child’s disability is not as obvious, or does not affect their academics.

The uncertainty of prognosis may lend itself to parents’ worry over their child’s future and ability to be independent, especially when the child becomes an adult (Patterson & Blum, 1996; Rolland, 2005). The heterogeneous nature of autism, and current lack of a definite
treatment and intervention to ‘cure’ autism can contribute to the high levels of stress and emotional and psychological distress parents of children with autism experience. As Rolland (2005) noted, “family coping and adaptation, especially future planning, are hindered by anticipatory anxiety and ambiguity about what will happen” (p. 496). For instance, families of adolescents with autism entering the postsecondary education or employment stage may find the different service systems challenging to navigate or access. They may also be concerned about the types of living arrangements that are available to their adult son or daughter with autism when they are no longer around (Gray, 2002).

Having other children with disabilities apart from the child with autism is likely to be another source of stress for parents (Bekhet et al., 2012; Orsmond et al., 2007). Having multiple children with disabilities not only puts a strain on the family’s financial and physical resources, it can also affect the parents psychologically and emotionally.

Other factors include limited or lack of supports such as respite care, and services, especially in adulthood. Mothers in a study examining psychological distress (Bromley, Hare, Davison, & Emerson, 2004) reported the need for help or more help (unmet needs) such as help with care during holidays, having a break, advice on caring for child and planning for child’s future. In their study, mothers reporting higher levels of unmet needs also tended to have children with greater severity of emotional distress and disruptive or antisocial behaviors, greater language delays and socialization impairments (Bromley et al., 2004).

**General Indicators of Resilience and Supports across the Life Cycle**

Despite these challenges, many families have been able to cope with the stress associated with having a child with autism. These families may exhibit intrinsic, resilient qualities, and also have access to formal and informal supports. Resilience has been described as “a process of coping with adversity, change, or opportunity in a manner that results in the identification, fortification, and enrichment of resilient qualities or protective
factors” (Richardson, 2002, p. 308). Although a lot of the literature has focused on the stressors parents of children with autism encounter, there has been increasing attention given to the supportive factors and resilience these families possess (Greef & van der Walt, 2010; King, Baxter, Rosenbaum, Zwaigenbaum, & Bates 2009). More recently, there has been a shift in focus from resilience in the individual to family resilience (McCubbin & McCubbin, 1996; Walsh, 2003), and more specifically, family resilience in families of individuals with autism (Bayat, 2007; Greef & van der Walt, 2010).

According to Walsh (2003) family resilience is the result of key processes where the family recovers and grows from persistent adversity affecting all members of the family. Thus family strengths are revealed at different points in the family life cycle. This highlights the need to understand strengths and stressors unique to each stage in the family life cycle. For interventions and treatments to be effective in helping families, they need to be not only family-centered, but time-sensitive as well.

Bayat’s (2007) study on family resilience in families of children with autism identified aspects of family resilience that concurred with Walsh’s (2003) framework of family resilience. These were having a sense of connectedness and pulling resources together, making positive meaning out of adversity, having a changed world view, gaining affirmation of their strengths and becoming more compassionate, and having a spiritual experience or belief system. The family’s ability to pull resources together to support the child with autism often led to a sense of being connected and united. This includes the ability to have open communication and to be flexible in accepting and adapting one’s role and responsibilities in the family to meet new demands that come along the way. Making positive meaning refers to the family’s ability to appreciate even the smaller achievements and to learn from the experience of caring for a child with autism. In Bayat’s (2007) study, the families cited examples such as acquiring new qualities, and learning lessons that ranged from personal to
inspirational. Families in the study also described having a changed world view, which was a philosophical shift in their outlook on the meaning and purpose of life. They also discovered specific strengths within themselves such as having more compassion and patience. Finding a new spiritual belief or being strengthened in their faith was the final component of resilience that was mentioned by these family members.

Besides having resilient qualities within the family, formal and informal supports also are key protective factors. During the early years, formal supports such as school services, therapy, and other agencies are more available and easily accessible. They are essential for the child’s development and building family competencies in caring for the child. Informal supports such as social support from other family members, friends and co-workers are important as well. In fact, their significance increases over the years as the availability and quality of formal supports decline (Gray, 2002) when the child transitions from adolescence to adulthood.

The availability of respite care impacting family coping and resilience was also mentioned in several studies (Gray, 2002; Meadan et al., 2010). Having access to respite care can reduce stress levels and increase parents’ ability to cope with caring for their child. It also provides more opportunities to engage in recreational and leisure activities, which have been reported to be lacking for parents of children with ASD (Gray, 2002). This points to the need to provide respite care for families where parents can take a break from their caregiving responsibilities and take the opportunity to rest and recharge themselves. In addition, creating opportunities for recreational activities for parents would need to consider how best to include the child with ASD.

Having a higher income also can be a supportive factor (Greef & van der Walt, 2010; Sipos, Predescu, Muresan, & Iftene, 2012). Across all the stages of the life cycle, particularly in the earlier years when services and interventions are more available, a higher income may
provide greater access to services and interventions outside of school. Not only will this allow parents to learn strategies for caring for their child, it may also provide some level of respite from their caregiving duties. During the child’s school-age years, the family may have been receiving some form of financial support from federal and state government sources. However, as the child gets older and enters adulthood, the reduced availability of mandated services means that parents will have to bear the financial costs of services and therapies (Neely et al., 2012). Having a higher income increases the accessibility of such services for the child, which in turn becomes a form of support for the family.

In addition, coping strategies employing a problem-focused or approach oriented method have been associated with better family adjustment where the individual actively seeks to address and resolve the stressor, or regulate their emotional responses to the stressor. These may include using positive reframing strategies and being optimistic. Conversely, avoidance techniques and emotion-focused strategies, where the individual denies, avoids, or diverts attention away from the stressor, have been associated with poorer outcomes in terms of lower family adaptability and cohesion, and increased depressive symptoms (Lin et al., 2011; Meadan et al., 2010). These strategies may change over time, due to changes in the nature and characteristics of the child and family’s needs as well as the availability and accessibility of treatment options (Gray, 2002).

Although there has been a substantial amount of research on various aspects of the challenges and supports parents of individuals with autism encounter especially at the early and middle childhood ages, there is need to integrate these findings to understand the range of and change in parents’ experiences across the life cycle stages. Having a cross-sectional, open-ended qualitative study provides a means to understand how these parenting experiences align with the different life cycle stages of the child with autism. Hence the goal of this study is to describe the challenges and supports parents of individuals with autism
experience that are unique to specific life cycle stages in order to understand how they differ at each stage and how these parents and their child with ASD may be better supported at each stage.
CHAPTER 3: METHOD

Research Questions

The purpose of this study was to understand the experiences of parents of individuals with moderate to severe ASD across the stages of the individual’s life cycle. More specifically, this study sought to address two research questions: What are the stressors and supports encountered by parents at each life cycle stage of the individual with moderate to severe autism? How do these supports and stressors change or remain constant across the life cycle stages?

Study Design

This qualitative study employed a multiple case study approach. As Yin (2003) notes, the case study approach allows us to “investigate a contemporary phenomenon within its real-life context, especially when the boundaries between phenomenon and context are not clearly evident” (p. 13). In this case, the stressors and supports experienced by families of individuals with autism are likely to be intricately linked to the severity of the symptoms related to autism as well as their present life cycle stage. A multiple case design was selected as it provides the potential for replication of findings across the different cases, which can enhance generalizability (Yin, 2003). In other words, themes that occur repeatedly across the different life cycle stages are more likely to be general themes encountered across all families of a child, adolescent, or adult with autism. In addition, a multiple case design may lead to “contrasting results but for predictable reasons” (Yin, 2003, p. 47). In the present study, this refers to any contrasting findings among parents as a result of their different life cycle stages or other factors such as having individuals with different types of behavioral symptoms associated with autism or family-specific issues (e.g., having siblings with disabilities). In
this instance, the multiple case study approach offers insights into the unique challenges and supports experienced by families of individuals with moderate-severe autism at each life cycle stage.

**Participant Recruitment**

Purposive sampling and snowball sampling methods were employed in this study to recruit parents of individuals with moderate to severe autism. Emails and flyers (refer to Appendix A) were sent to organizations working with families of individuals with autism in a mid-southeastern state in the U.S., inviting parents of individuals with moderate to severe autism to participate. This form of purposive sampling allowed for a more targeted recruitment. The organizations contacted included the Carolina Institute for Developmental Disabilities, Family Support Network, TEACCH, the Autism Society of North Carolina, and Extraordinary Ventures. Emails and letters contained a cover page explaining the purpose of the study and requesting interested parents of children, youth, or adults with autism to contact the researcher through email or phone.

In order to increase response rate, the snowball sampling method was also employed. The author’s colleagues and parent participants were asked if they would disseminate information about this study to other parents who may be eligible and might be interested in participating. Some of the contacts from the organizations also offered to disseminate information about the study to parents they personally knew. One of the contact persons also offered to post information about the study on a Facebook page dedicated to parents raising children with autism and containing information about autism resources.

The recruitment period lasted from mid December 2013 to early February 2014. Initially, two rounds of parent recruitment were conducted (one at the end of December, and another in January). In late January and early February, flyers and emails requesting specifically for parents of adults with moderate to severe ASD were distributed due to the
lack of response from parents of adults. Overall, a total of 22 parents contacted the researcher expressing interest in the study. Of these, 11 completed the SRS-2. Finally, a total of eight families (nine parents) were eligible to participate and consented to participate in the study, with two representing each of the four life cycle stages. In one family, both the father and mother requested to be interviewed, yielding a total number of nine parent participants.

**Ethics and Reciprocity**

Due to the personal nature of this study, it was imperative that ethical concerns were highlighted and addressed. First, informed consent from participants was obtained prior to the data collection. A copy of the consent form is provided in Appendix B. The purpose of the research was made clear to parents through an information sheet sent to them when they first contacted the researcher.

Larossa, Bennett, and Gelles (1981) suggested that qualitative family research might resemble a therapy session where the interviewees begin to cast the researcher as more than just a researcher, creating unrealistic expectations. Thus the student researcher ensured that parents understood she was not a service provider or interventionist and would not be able to intervene for their children or speak to schools on their behalf. For example, some participants mentioned at the end of the interview that the interview had been therapeutic for them, giving them an avenue to talk at length about their concerns and share their successes, as well as make suggestions on what would have been helpful for them. Hence the researcher clarified again that this interview would not lead to specific interventions or have a direct impact on policies, which was understood by the participants. For these participants, the interview provided them with a listening ear and a period of time where they could share their experiences.

Second, a major ethical consideration was the risk-benefit equation (Larossa et al., 1981) where researchers need to make every effort to ensure that risks are minimized and
potential benefits outweigh the risks. One of the major risks relevant to this present study was the public exposure of the family’s private life. In order to address the risk of public exposure, it was crucial that the personal details of these families be kept confidential and anonymous while their views were accurately represented. With regards to the former, this meant that any identifiable information was removed prior to the analysis stage to maintain participant anonymity. In addition, participants were provided the opportunity to review the transcript and a summary of the themes from their respective interviews. This allowed them to correct any misrepresentation that may have been a result of this student researcher’s own perspectives, personal biases, or past experiences. To acknowledge the contribution made by the parents as collaborators in this research, they were given a gift voucher from local stores and a list of helpful resources. Resources included contacts of autism-related organizations (e.g., Autism Speaks, Autism Support Network), information on apps that are either general or targeted at specific developmental skills (e.g., Autism Apps Wheel), and links to other useful resources. A copy of this resource list is provided in Appendix C. In one instance, a parent requested specifically for, and was emailed, the PDF copy of the Autism Apps Wheel.

**Instrumentation**

**Screening measure.** Parents who responded to the recruitment emails or flyers were first asked to complete a 65-item Social Responsiveness Scale - second edition (SRS-2, Constantino & Gruber, 2012). This served as a screening measure to verify the severity of their child’s autism symptoms. The SRS-2 was selected because impairment in social communication and interaction is a key feature of ASD. This scale is a widely used autism assessment completed by a parent or teacher that identifies social impairment in ASD and its severity level. It also contains a DSM-5 compatible scale. The SRS-2 consists of forms for specific age groups: preschool (ages 2.5-4.5), school-age (ages 4-18), and adult (ages 19 and above). Internal consistency ratings for each of these parent-report forms have been reported.
to be .88 for the preschool form, .91 to .97 for the school-age form, and .89 to .96 for the adult form (Constantino & Gruber, 2012). The SRS-2 scores reported by all participants fell in the severe range. The individual scores of participants will be presented together with the child demographics in the Results section.

**Demographic forms.** Participants were asked to complete a demographic form to provide information about the parent, family, and child characteristics. The parent section included items such as parents’ age and ethnicity, marital status, educational level, health status, occupation, and household income range. The family section contained items regarding the age and gender of the family members, number of siblings, and health status of family members. Parents of children or youths with autism (aged 19 and below) completed a child characteristics section containing items such as the child’s age and gender, type of diagnosis, age of diagnosis, severity of autistic symptoms, presence of comorbid or co-occurring disorders, and their current educational level. Parents of adults with autism (aged 20 and above) completed a child characteristics section consisting of the same items, but replacing current educational level with highest educational level completed, current occupation, current living arrangements, marital status, and annual income range. An example of the demographic form for both parents of children/youths with ASD and parents of adults with ASD can be found in Appendix D.

**Semi-structured interview.** The interview consisted of semi-structured questions that focused on the following areas: a) a description of the child, b) the parent’s expectations, goals, or dreams for the child, c) stressors and challenges encountered, d) supportive factors experienced, e) how the stressors and supports experienced have changed over time (for parents of older children, adolescents, and adults), f) what forms of supports would have been helpful at each stage, g) what personal strengths had helped them along this journey, and h) what advice they would have for parents going through the same journey. Table 1 shows the
interview questions in relation to the research questions. The interview protocol is included in Appendix E. These questions served as a guideline for the interview.

**Table 1**

*Interview Questions*

<table>
<thead>
<tr>
<th>Research Question</th>
<th>Interview Question</th>
</tr>
</thead>
<tbody>
<tr>
<td>Getting to know your child</td>
<td>Please describe your child with autism. Does your child get along well with other children? How is your child doing in school/ work/ other setting?</td>
</tr>
<tr>
<td>What expectations, goals, or dreams do you have for your child?</td>
<td>What are some of your expectations, goals, or dreams for your child with autism now at age ____? How have they changed over the years?</td>
</tr>
<tr>
<td>What are stressors or challenges encountered? How have these changed over time?</td>
<td>What are some of your concerns regarding your child with autism now at age ____? How have these concerns changed from when your child was younger (time of diagnosis, middle childhood, adolescence)?</td>
</tr>
<tr>
<td>What are sources of support encountered? How have these changed over time?</td>
<td>What are some of your child and family successes now? What are some sources of support or strength for you in dealing with your child with autism? What were some internal strengths you feel you, your child, or your family possessed that helped you in this journey?</td>
</tr>
</tbody>
</table>

**Materials**

All interviews were recorded using a digital audio recorder and transcribed. Analysis of the transcripts was conducted on NVivo, a qualitative data analysis software. NVivo was chosen because it allows the researcher to organize the data and create themes, which can be unstructured or hierarchical. This gives the researcher flexibility in analyzing the transcripts and organizing the themes throughout the analytical process. In addition, NVivo allows for blind coding by multiple coders, where coders individually code the same data before their codes are compared for reliability purposes.
**Procedure**

Parents who contacted the researcher were sent an information sheet providing details of the study and what their participation would entail. They were also asked to complete the SRS-2 as a screening measure to verify the severity level of their child’s symptoms related to autism. Upon confirmation that the child’s level of severity met the requirements for this study (i.e., moderate to severe autism), a meeting date, time, and location for the interview was arranged. Parents chose the location for the interview, which could be at their home or outside, depending on their preference. The purpose of giving parents the option to be interviewed in their home was to help them feel more at ease in relating their personal stories and reduce any distress that might occur during the interview (Larossa et al., 1981). Most parents elected to have the interviews in locations convenient for both the parent and the interviewer, which were in a local \( n = 2 \) or university library \( n = 4 \), the participant’s home \( n = 1 \), or at a café \( n = 2 \).

The primary mode of data collection was the use of in-depth interviews with parents, which have the advantage of letting participants provide detailed descriptions of their personal experiences (Creswell, 2011). Participants were also encouraged to bring to the interview any artifacts or documentation they felt would be useful in providing a better understanding of their experiences in supporting the individual with autism. Sample artifacts and documents included photographs, school records, evaluation reports, teacher notes about their child, or work produced by their child. These artifacts served to support the information from the interviews. For example, in order to demonstrate the school’s reluctance to provide services in order to keep their costs low, a parent had brought two evaluations that had been conducted on her child – one from the school and the other from a private psychologist, each of which had vastly different conclusions.
At the onset of individual interviews, participants were asked to sign a consent form indicating their willingness (a) to participate in the study, (b) for the interview to be audio recorded, and (c) for a copy of the documents or artifacts they bring (if any) to be made. They were then asked to complete the demographic form. The interviews were recorded and lasted between 1 hour and 2.5 hours. Semi-structured questions were used to guide the interviews while still allowing for some degree of flexibility to delve deeper into the issues parents raised.

The student researcher also recorded field notes during the interview. These notes included questions for clarification, key discussion points, and key themes, which allowed for further inquiry and helped to clarify points discussed earlier in the interview. For instance, toward the end of each interview, the researcher would give a summary of the points discussed. She also took the chance to ask questions to clarify any points that had been unclear. Additional notes also were written directly after the interview when parents mentioned issues or useful information after the recording had ceased. In addition, the student researcher also wrote down some reflections on the possible themes soon after the interviews. Recording thoughts and reflections immediately after the interviews allow for greater accuracy of the notes taken earlier and was a useful resource during data analysis. An example of the field notes is provided in Appendix F.

At the end of each interview, parents were given a list of helpful resources and a $20 gift voucher to thank them for their time and willingness to share their personal stories. Parents were also informed that they would receive a copy of the transcript and a summary of the issues discussed for their verification. They also were asked if they want to be informed of the results of the study. Six parents requested to be sent a summary of the study results.
Data Analysis

The interview audio recordings were transcribed and the researcher, as the interviewer, reviewed the transcripts for accuracy. As recommended by Rubin (2005), any thoughts or reflections that occurred when reviewing the transcripts were recorded. A copy of the transcript and a summary of the issues discussed were sent to the respective participants for verification. The summary included a description of the child, parent expectations, and a table outlining the challenges and supports they experienced over time. An example of the summary is provided in Appendix G. Parents were asked to review the transcript and were given the option of reviewing the summary as well. They were asked to correct any mistakes found and to include additional thoughts or information not included in the transcripts. This form of member checking was used to establish credibility of the data. Minor changes were made, primarily to the spelling of actual service provider names. One parent had not responded to requests for verification of the data. To protect confidentiality, the names of parents and their children were replaced with pseudo-names after verification and prior to analysis.

Before beginning the analysis, the researcher read the transcript at least once before coding to become familiar with the content. The transcripts were imported into NVivo and examined line-by-line, using open coding to identify emerging themes and form main categories and sub-codes (Corbin & Strauss, 1990; Rubin, 2005). Preliminary themes based on the research questions included child-related, parent-related, or external factors that contribute to parental stress or support. Examples of sub-codes for “stressors” included challenging behaviors and co-morbid disorders or medical issues (child-related stressors), balancing work and caregiving responsibilities (parent-related stressors), unsupportive schools or teachers (school-related stressors), accessibility and availability of services and service providers (service-related stressors). Examples of sub-codes for “supports” included
informal supports from family (e.g., spouse, other children), extended family or friends, and formal supports such as schools, services and service providers. Additional supports included parent strengths or indicators of resilience. For a full list of the themes and sub-codes, please refer to Appendix H. Appendix I presents a sample of the themes and relevant quotes. Due to the iterative nature of the analytical procedure, the themes and sub-codes evolved during the analytical process, informing subsequent interviews. Hence data analysis and interviews were conducted concurrently.

During the analytical process, the researcher also made reflective, thematic memos. Marshall and Rossman (2011) encourage making notes during analysis because “writing notes, reflective memos, thoughts, and insights is invaluable for generating the unusual insights that move the analysis from the mundane and obvious to the creative” (p. 213). Noting down thoughts and questions about the data helped the researcher “to identify categories that subsume a number of initial codes” (Marshall & Rossman, 2011, p. 213) as well as detect relationships among the emerging themes.

Copies of the artifacts and documents such as evaluation reports and notes from teachers were used as secondary data to supplement the themes and sub-codes generated. As Marshall and Rossman (2011) caution, “the meaning of the documents is never transparent” (p. 161). A limitation of analyzing documents and artifacts was the extent of inferential reasoning required as analysis of documents and artifacts “entails interpretation by the researcher” (Marshall & Rossman, 2011, p.162). To address this limitation, parents were asked to explain the significance of the document or artifact to them, if they had not already done so. Second, the documents and artifacts were not used to form key themes. Instead, they were used to support the themes and codes generated.

Once no further main themes or sub-codes could be generated, the data was considered to have reached theoretical sufficiency (Dey, 1999), where no further themes
could be elicited from the data. The analytical process was then considered complete. The themes and sub-codes generated were used to formulate overarching themes that addressed the key research questions of what stressors and supports parents of children with autism experience, and how they differed or remained constant across the life cycle stages.

In order to reduce researcher bias, an external coder was recruited for reliability coding after the researcher had coded all transcripts. The external coder was a senior majoring in psychology who had taken three classes where issues surrounding the autism diagnosis, treatment, and resources for families had been discussed. She was also personally familiar with an individual with autism. Having an external coder ensured that biases as a result of the researcher’s personal experience, background, and beliefs were minimized. The external coder could also provide additional insights overlooked by the researcher. Before beginning the coding process, the external coder was trained in using the NVivo software. Training consisted of teaching her to code in NVivo and to create codes should the need arise, and practicing coding with the researcher’s codes using a sample transcript. The external coder was also required to read the transcript at least once prior to coding. A list of the key themes and the accompanying descriptions generated by the researcher was provided, which was used by the external coder when coding the transcripts (see Appendix H). The external coder was informed that she could generate new themes if they emerged. About half of the transcripts, one from each of the life cycle stages and two from the adolescent stage (which had three parent interviews), were coded for reliability. The codes generated by the external coder were then compared to those of the primary researcher. The external coder did not create new themes.

Kappa scores and percentage agreement for the codes are presented in Table 2. Percentage agreement in NVivo is the percentage of agreement (characters) that was coded and uncoded divided by the total number of characters in the document. The kappa score,
Table 2.
Kappa Scores and Percentage Agreement for Reliability Coding

<table>
<thead>
<tr>
<th>Theme</th>
<th>kappa</th>
<th>% Agreement</th>
</tr>
</thead>
<tbody>
<tr>
<td>expectation, goals, dreams, hopes</td>
<td>0.63</td>
<td>96.46</td>
</tr>
<tr>
<td>stress – child</td>
<td>0.59</td>
<td>90.76</td>
</tr>
<tr>
<td>stress - extended family</td>
<td>0.4</td>
<td>99.77</td>
</tr>
<tr>
<td>stress - family nuclear</td>
<td>0.27</td>
<td>98.17</td>
</tr>
<tr>
<td>stress – finance</td>
<td>0.64</td>
<td>98.97</td>
</tr>
<tr>
<td>stress - friends - lack of support, loss of friendships</td>
<td>1.00</td>
<td>100.00</td>
</tr>
<tr>
<td>stress - gov't - general, unhelpful</td>
<td>1.00</td>
<td>100.00</td>
</tr>
<tr>
<td>stress - macro - state-level systemic issues</td>
<td>0.4</td>
<td>99.46</td>
</tr>
<tr>
<td>stress – parent</td>
<td>0.2</td>
<td>95.65</td>
</tr>
<tr>
<td>stress - school, teacher, staff</td>
<td>0.12</td>
<td>97.16</td>
</tr>
<tr>
<td>stress - service provider, services</td>
<td>0.31</td>
<td>96.15</td>
</tr>
<tr>
<td>stress - social – isolation</td>
<td>0.8</td>
<td>99.93</td>
</tr>
<tr>
<td>stress - societal - lack of understanding</td>
<td>0.73</td>
<td>98.87</td>
</tr>
<tr>
<td>support - formal – financial</td>
<td>0.67</td>
<td>99.59</td>
</tr>
<tr>
<td>support - formal – school</td>
<td>0.5</td>
<td>97.07</td>
</tr>
<tr>
<td>support - formal - service, service provider</td>
<td>0.52</td>
<td>93.83</td>
</tr>
<tr>
<td>support - informal – child</td>
<td>0.31</td>
<td>97.19</td>
</tr>
<tr>
<td>support - informal – church</td>
<td>1.00</td>
<td>100.00</td>
</tr>
<tr>
<td>support - informal - extended family</td>
<td>0.99</td>
<td>99.94</td>
</tr>
<tr>
<td>support - informal - family nuclear</td>
<td>0.62</td>
<td>97.94</td>
</tr>
<tr>
<td>support - informal – friend</td>
<td>0.8</td>
<td>98.79</td>
</tr>
<tr>
<td>support - location - resource-rich</td>
<td>0.35</td>
<td>98.39</td>
</tr>
<tr>
<td>support - other - for parent</td>
<td>0.47</td>
<td>98.64</td>
</tr>
<tr>
<td>support - other - parent work - understanding environment, self-employed</td>
<td>0.88</td>
<td>99.8</td>
</tr>
<tr>
<td>support - resilience - child strength - resilience, perseverance</td>
<td>0.88</td>
<td>99.85</td>
</tr>
<tr>
<td>support - resilience - family strengths - adjust, adapt, accommodate</td>
<td>0.2</td>
<td>98.27</td>
</tr>
<tr>
<td>support - resilience - parent strength</td>
<td>0.34</td>
<td>89.41</td>
</tr>
<tr>
<td>OVERALL</td>
<td>0.59</td>
<td>97.83</td>
</tr>
</tbody>
</table>

however, takes into consideration the fact that coders may agree or disagree by chance, with a score of 1 indicating perfect agreement and 0 indicating agreement due to chance. Kappa scores ranged from 0.12 to 1.00 across the themes, with an overall Kappa score of .59, which is considered to be moderate agreement. There was only slight agreement on the two themes of parent-related (0.20) and school-related (0.12) stress. As Viera and Garrett (2005) noted, it is possible for discrepancy between kappa scores and percentage agreement to occur as kappa scores are affected by prevalence. This may be the case for the two low scores in this study,
as the percentage agreement was high for both themes (95.40% and 99.67% respectively).

The researcher then reviewed the themes and met with the external coder to discuss discrepancies in coding. The researcher and external coder managed to reach consensus on all discrepancies. Some of the coding for specific texts was shifted from one theme to another after discussion, although it was often texts were coded under multiple themes.

Once this analytical procedure was completed, the themes were organized according to the different life cycle stages. The researcher reviewed themes to arrive at overarching themes within each life cycle stage and across stages. The next section presents the key findings from the interviews.
CHAPTER 4: RESULTS

The purpose of this study was to understand the stressors and supports parents of individuals with moderate to severe autism at the different life cycle stages experience. Similarities and differences in stressors and supports across the stages were also explored. A total of nine parents from eight families were interviewed for this study, with two families from each life cycle stage. During the interviews, parents described their expectations and hopes for their child as well as the stressors and supports they encountered from early childhood to the present. This chapter will begin with a description of the participants’ characteristics. Next, stressors and supports specific to each life cycle stage will be presented. The last section will present stressors and supports overlapping across the ages.

Participant Characteristics

Parent and family demographics. Participants consisted of seven mothers and two fathers from eight families with individuals with moderate to severe ASD. All parents were Caucasian except for one mother and one father (from the same family) who were African American. Participants’ ages ranged from 33 to 58 years. The marital status of the families consisted of six families in which parents were married (including on family in which the parents were considering a separation), and two parents who were divorced. Their household income ranged from below $50,000 per year to above $125,000 per year. The number of children each family had ranged from one to four, with two families who had another child with a disability. An outline of the parent and family demographics and characteristics is presented in Table 3.

Child/youth/adult demographics. The ages of the individuals with ASD ranged from 5 to 23 years, with the ages of diagnosis ranging from 21 months to 12 years. Three
<table>
<thead>
<tr>
<th>Life cycle stage</th>
<th>Child name</th>
<th>Parent name</th>
<th>Parent Age</th>
<th>Ethnicity</th>
<th>Marital status</th>
<th>Highest educational level attained</th>
<th>Health status</th>
<th>Occupation</th>
<th>Annual household Income range</th>
<th>Number of children</th>
<th>Number of other children with disabilities</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early Childhood</td>
<td>Mark</td>
<td>Sarah</td>
<td>33</td>
<td>Caucasian</td>
<td>married</td>
<td>professional degree</td>
<td>good</td>
<td>attorney</td>
<td>$90,000-$124,999</td>
<td>2</td>
<td>0</td>
</tr>
<tr>
<td>Early Childhood</td>
<td>Alice</td>
<td>Mary</td>
<td>38</td>
<td>Caucasian</td>
<td>divorced</td>
<td>high school, current college student</td>
<td>fair</td>
<td>none-stay at home mother; disabled veteran; student</td>
<td>&lt; $50,000</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Middle Childhood</td>
<td>Lizzy</td>
<td>Eric</td>
<td>43</td>
<td>Caucasian</td>
<td>married</td>
<td>4 yr college</td>
<td>good</td>
<td>database administrator</td>
<td>$90,000-$124,999</td>
<td>3</td>
<td>0</td>
</tr>
<tr>
<td>Middle Childhood</td>
<td>Aiden</td>
<td>Rose</td>
<td>37</td>
<td>Caucasian</td>
<td>married</td>
<td>2 yr college</td>
<td>good</td>
<td>stay at home mom</td>
<td>&lt; $50,000</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Adolescence</td>
<td>Leroy</td>
<td>Joan*</td>
<td>41</td>
<td>African American</td>
<td>married</td>
<td>doctoral degree</td>
<td>good</td>
<td>university professor</td>
<td>$90,000-$124,999</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Adolescence</td>
<td>Leroy</td>
<td>John*</td>
<td>-</td>
<td>African American</td>
<td>married</td>
<td>doctoral degree</td>
<td>good</td>
<td>professor</td>
<td>$90,000-$124,999</td>
<td>4</td>
<td>0</td>
</tr>
<tr>
<td>Adolescence</td>
<td>Carl</td>
<td>Sharon</td>
<td>50</td>
<td>Caucasian</td>
<td>married</td>
<td>masters degree</td>
<td>good</td>
<td>stay at home mom</td>
<td>&gt; $125,000</td>
<td>3</td>
<td>0</td>
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<tr>
<td>Adulthood</td>
<td>Nick</td>
<td>Grace</td>
<td>54</td>
<td>Caucasian</td>
<td>divorced</td>
<td>4 yr college</td>
<td>good</td>
<td>community guide</td>
<td>$50,000-$69,999</td>
<td>2</td>
<td>1</td>
</tr>
<tr>
<td>Adulthood</td>
<td>Luke</td>
<td>Sadie</td>
<td>58</td>
<td>Caucasian</td>
<td>married</td>
<td>2 yr college</td>
<td>good</td>
<td>retail</td>
<td>$70,000-$89,999</td>
<td>1</td>
<td>0</td>
</tr>
</tbody>
</table>

* Joan and John are from the same family
individuals were diagnosed with Pervasive Developmental Disorder Not Otherwise Specified (PDD-NOS) and five were diagnosed with Autistic Disorder (AD). Two of the five had an earlier diagnosis of PDD-NOS. Most participants were first diagnosed between 21 months and 4 years. However, two individuals were diagnosed at later ages (8 and 12 years). The first was due to the parent’s refusal to accept an autism diagnosis because her child did not meet one of the criteria for autism in the DSM-IV-TR (APA, 2004) criteria. The second was due to an unawareness of autism in parents and service providers who were living in a developing country at that time. Although the SRS-2 scores for all individuals met the criteria for the “severe” range, the severity level of autism symptoms for seven individuals were described by their parents as being in the moderate severity level. One child was described as “usually moderate but severe on her worst day”, and another child was described as being in the “severe range”. This discrepancy may be due to the SRS-2 being more specific to the children’s social responsiveness, while parents may be attending to other factors beyond social symptoms, such as daily or cognitive functioning. Alternatively, parents may view their children through a different lens as they may consider the overall progress their child has made since or prior to the time of diagnosis and overestimate their functioning levels. As one parent articulated, she took into account the progress her child had made and hence considered her child to be functioning at a higher level than implied by the SRS-2 scores. All except two individuals, Sarah’s son, Mark, and Joan and John’s son, Leroy, had multiple disabilities (e.g., intellectual disability, attention-deficit, hyperactivity disorder (ADHD), obsessive compulsive disorder (OCD), sensory processing disorder) or medical complications (e.g., epilepsy, mitochondrial disease, cerebral foliate deficiency). The occupation of the two young adults with autism in this study, Nick and Luke, included office work and pastry chef, and laundry work at an autism-related organization respectively, both drawing an annual income below $50,000. Both adults are currently single and live with their parents. An
<table>
<thead>
<tr>
<th>Life cycle stage</th>
<th>Child name</th>
<th>Age</th>
<th>Diagnosis</th>
<th>Age of diagnosis</th>
<th>Severity level (parent-reported)</th>
<th>SRS-2 severity range (t-score)</th>
<th>Other disability/health issues</th>
<th>Current / highest educational level attained</th>
<th>Current occupation</th>
<th>Living arrangement</th>
<th>Marital status</th>
<th>Annual income range</th>
</tr>
</thead>
<tbody>
<tr>
<td>Early Childhood</td>
<td>Mark</td>
<td>5</td>
<td>AD</td>
<td>3 years</td>
<td>Moderate</td>
<td>Severe (86)</td>
<td>None</td>
<td>Preschool</td>
<td>na</td>
<td>na</td>
<td>na</td>
<td>na</td>
</tr>
<tr>
<td>Early Childhood</td>
<td>Alice</td>
<td>7</td>
<td>AD</td>
<td>21 months</td>
<td>Moderate-severe (on worst day)</td>
<td>Severe (&gt;90)</td>
<td>SPD, anxiety, complex medical issues Intellectual disability</td>
<td>Elementary</td>
<td>na</td>
<td>na</td>
<td>na</td>
<td>na</td>
</tr>
<tr>
<td>Middle Childhood</td>
<td>Lizzy</td>
<td>10</td>
<td>AD</td>
<td>4(PDD-NOS); 8 years (AD)</td>
<td>Severe (88)</td>
<td></td>
<td></td>
<td>Elementary</td>
<td>na</td>
<td>na</td>
<td>na</td>
<td>na</td>
</tr>
<tr>
<td>Middle Childhood</td>
<td>Aiden</td>
<td>10</td>
<td>PDD-NOS</td>
<td>34 months</td>
<td>Moderate</td>
<td>Severe (85)</td>
<td>ADHD; mildly mentally handicapped</td>
<td>Elementary</td>
<td>na</td>
<td>na</td>
<td>na</td>
<td>Na</td>
</tr>
<tr>
<td>Adolescence</td>
<td>Leroy</td>
<td>16</td>
<td>PDD-NOS</td>
<td>3.5 years</td>
<td>Moderate</td>
<td>Severe (78/81*)</td>
<td>None</td>
<td>High school</td>
<td>na</td>
<td>na</td>
<td>na</td>
<td>Na</td>
</tr>
<tr>
<td>Adolescence</td>
<td>Carl</td>
<td>17</td>
<td>PDD-NOS</td>
<td>12 years</td>
<td>Moderate</td>
<td>Severe (83)</td>
<td>Epilepsy</td>
<td>High school</td>
<td>na</td>
<td>na</td>
<td>na</td>
<td>Na</td>
</tr>
<tr>
<td>Adulthood</td>
<td>Nick</td>
<td>21</td>
<td>AD</td>
<td>3 years</td>
<td>Moderate</td>
<td>Severe (80)</td>
<td>Petite mal seizures</td>
<td>High school</td>
<td>Pastry chef, office work</td>
<td>Living with parents</td>
<td>Single</td>
<td>&lt; $50,000</td>
</tr>
<tr>
<td>Adulthood</td>
<td>Luke</td>
<td>23</td>
<td>AD</td>
<td>8 years</td>
<td>Moderate</td>
<td>Severe (89)</td>
<td>OCD; epilepsy</td>
<td>High school</td>
<td>Laundry work at autism organization</td>
<td>Living with parents</td>
<td>Single</td>
<td>&lt; $50,000</td>
</tr>
</tbody>
</table>

*Note. AD: Autism Disorder; PDD-NOS: Pervasive Developmental Disorder – Not Otherwise Specified. SRS-2 t-scores indicate: 60-65 = mild; 66-75 = moderate; >76 = severe. 
* Both Joan and John rated Leroy, producing t-scores of 78 and 81 respectively.
overview of the child demographics and characteristics according to the child’s age level is presented in Table 4.

**Key Themes at Each Life Cycle Stage**

The following section will present the key themes of stress and support that parents experienced at each life cycle stage of the child. Many themes overlapped across stages. For instance, themes at the middle childhood stage tended to be similar to themes in the early childhood stage; themes in the adolescence stage also overlapped with those at the adulthood stage. Hence, the following section will discuss the key themes for early and middle childhood, while highlighting themes unique to each stage. Likewise, key themes for the adolescence and adulthood stages will be discussed together and themes that were specific to each stage will be highlighted.

**Early childhood stage.** Themes in the early childhood stage centered on the period of diagnosis and adjustment to the diagnosis. Apart from child-related difficulties, parents at this stage were new to the early intervention system and faced challenges as they encountered unsupportive service providers or had difficulties accessing and navigating services. In addition several parents experienced a loss of friendships. However, informational supports from service providers and parent education classes, as well as having a family-oriented program were particularly useful at this stage as they provided parents of newly diagnosed children critical information about autism and equipped them with tools and strategies to support their child.

**Child-related factors.** Child-related stressors included having to deal with the child’s challenging behaviors, the need for constant parental attention, as well as multiple disabilities, medical issues, or developmental lag, which made the need for early intervention more pressing. Those stressors are presented below.
**Challenging behaviors.** Behaviors parents found difficult included irregular sleep patterns, tantrums or meltdowns, sensory-seeking and other strange behaviors. Irregular sleep pattern was a stressor Sarah, Eric, Rose, and John had in common. Their children’s disturbed sleep also meant the parents did not get sufficient rest themselves. It had been especially stressful for Rose, whose husband was often away for work, because Aiden, at one year old, not only had a pattern of sleeping only 3-4 hours a night, but also had night terrors and would only sleep when Rose was with him. Sarah’s relief at her son’s current ability to sleep was an indication of how much of a stressor it had been: “I’m glad he sleeps [now] because that’s the one thing I couldn’t deal with.”

Child tantrums, meltdowns, and unusual behaviors also were stressful for Sarah, Eric, Rose, John, and Sadie as it was difficult to calm their child. Parents learned to be vigilant to anything that would trigger a meltdown. For instance, John’s adolescent son, Leroy had lost a balloon when he was in preschool. For weeks after that, he would have a meltdown whenever he saw a balloon – “then how do you comfort him, how do you deal with that.” Sensory-seeking behaviors were another common challenge, including dumping behaviors, fecal smearing, and creating messes in the house (Sarah, Mary, Eric, and Rose). Rose, the mother of 10-year-old Aiden, commented that when he was younger, “you can’t turn your back for a split second because he will do something”. Rose and Sharon also recalled ‘bizarre’ behaviors such as Aiden eating inedible materials (books and clothes) as a toddler, and Carl, Sharon’s son, removing his clothes in the bathroom and refusing to return to class in elementary school.

Challenging behaviors were especially difficult for Rose, Grace, and Sadie when their child regressed developmentally and they did not know why. Sadie recalled that a day after her son, Luke, had his vaccination shots at 18 months old, he had a seizure, and according to Sadie, he lost his “giggly” personality. Similarly, Rose’s son, Aiden, lost his speech and
regressed in his gross and fine motor skills two weeks after his immunization shots at 14 months. Although some of his speech was regained after two weeks, “they’re not what they were”.

“Autism blinders”: Lack of safety awareness. The tendency to wander or, as Mary said, “autism blinders”, and the lack of safety awareness were concerns raised by parents across the ages (Sarah, Mary, Eric, Rose, and Sadie). The child’s inclination to dart off or to wander without regard for their safety was stressful as parents had to safe-proof their house and car, and also constantly ensure their child’s safety. Mary even purchased a bed that would zip Alice in so she would not wander out of the house at night. These wandering and safety issues meant parents were always on the lookout for their child’s safety, which heightened their stress levels.

Need for constant attention. Challenging child behaviors and the child’s lack of safety awareness meant parents had to be constantly vigilant. This was stressful for Mary, Rose, John, and Grace especially when they had to run errands while looking after the child. Mary explained, “I don’t have children that just come home and go off and do their own thing in their room like regular kids. They require intervention and attention constantly.” Grace recalled her experience when Nick was young,

when I go out with him, it's a nightmare. And even at home he needs to be occupied all the time. It felt like I had someone attached to my leg because wherever I went he was there […] Other than when he was asleep, he was with me. And it was constant.

Medical issues, multiple disabilities, and developmental delay. As seen in the demographics, several of the children had medical issues or multiple disabilities. At the early childhood stage, parents mentioned health issues such as refusing to eat and failure to thrive (Sarah, and Eric) or medical conditions (Mary, Sharon, and Grace). Sarah recalled when Mark was about one year old, “what was really stressful was him not eating for like a year and a half” and therefore not gaining weight. Finding the underlying reason and treatment for
these health issues was difficult for the parents. Mary’s two children have other medical complications in addition to autism. As Mary said, “80% of my life is managing their health.”

Realizing their child was developmentally behind same-age peers was a great concern for Sarah and Sadie when they first joined a preschool and a Mummy and Me group, respectively. However, Eric and Mary were not surprised that their children were behind other children developmentally because their respective daughters’ developmental challenges were evident from birth. As Eric said, “any diagnoses that we’ve gotten for her was never a surprise”. Nonetheless, parents were anxious to secure services and supports as soon as possible to address these developmental delays. Sarah recalled the pressure she felt in having to obtain supports for her son:

when they’re diagnosed, there is just an immense amount of pressure for you to get them as much therapy as you can. But it takes a lot of time, and it also takes a lot of money. And the stakes are really high too […] because the more therapy and intervention a kid gets when they’re young, the less likely it is that down the road they’re going to need more support.

These child-related factors were challenging for parents as they had to provide constant attention and felt pressure to obtain services and supports for the child to address the developmental delays. Apart from child-specific issues, parents also mentioned stressors concerning their reaction and adjustment to the diagnosis.

_Parent-related factors._ Parent-related stressors specific to the early childhood included their reactions to the diagnosis as parents’ pre-diagnosis frustration at not knowing what was wrong turned into grief upon receiving the diagnosis. For some parents, there was also relief at knowing what they needed to do next. Parents also reported experiencing a loss of support from friends at this stage. The difficulties associated with single parenthood were also mentioned by the two single parents in this study, especially when raising very young children.
Reaction and adjustment to diagnosis. Parents recalled varied reactions to their child’s autism diagnosis such as denial, shock, grief, and even blame. Sarah and Mary talked about going through a period of grieving after receiving the diagnosis because, in Sarah’s words, “you realize that the life that you thought your child was going to live might look different”. Grace also commented, “It was hard because I realized that he was always going to be a challenge.” Despite suspecting their children had autism, both Mary and Sadie had hoped for another reason for their child’s behaviors. As Mary admitted, “I really wanted to believe that she didn’t. But she did. I knew she did.” Sadie had refused to let her son, Luke, be labeled as having autism until he was in middle school. Furthermore, the chair of child development at the State University had negated the initial report the psychologist had given her, and she had clung to the chair’s positive report as her “life raft”.

In hindsight, parents noted that their own lack of autism awareness had been a source of frustration because they had not known what was wrong and how to help their child. For Sarah, Eric, and Grace, the medical or health problems their child had at that time, coupled with their lack of in-depth knowledge about autism, caused them to overlook the autism-related symptoms. Particularly bittersweet was Sharon’s sense of having “missed the boat” in early identification and hence, appropriate early intervention for her son that may have proved beneficial.

The frustration with not knowing what was wrong may explain why the diagnosis had been both a stressor and a relief for Rose, Sharon, and Grace. Despite their dismay at the diagnosis, having it helped them know what they needed to do, and also provided supports for the child and family. As Grace explained, “before I was just trying to deal with him on my own […], trying to lead as normal of a life as we could lead, but never knowing when he going to […] let all hell break loose. So by getting a diagnosis we also got some therapy and we got some treatment.”
Loss of friendships. The early childhood stage was also a period where parents (Mary, Grace, and Sadie) sometimes experienced a loss of friendships and a gradual change in their friendships. This happened either as a result of a lack of understanding (Mary and Grace) or because of relocation to other states (Sadie). Mary reasoned that these friends may have not known how to relate to the family impacted by autism. Grace summarized it this way, “My friends couldn’t handle it. I lost most of my friends. My friends then became other parents who had kids with autism or another disability.”

Single parenting. At the early childhood stage, single parenting may have been challenging for Mary and Grace because they were still adjusting to having at least one young child who needed constant attention and had autism as well, but had no other adult in the house for emotional and practical support. Incidentally, both Mary and Grace had another older child with disabilities. As Mary expressed, “There isn’t another person just to support me and help me and be there for me during the tough days. […] And that’s hard. […] I’m the only one doing this.”

Service delivery factors. Service delivery factors contributing to stress included parents’ unfamiliarity with the early intervention system, and difficulties accessing and navigating services. Service providers were both a stressor and support depending on the extent of their knowledge about autism and attitudes toward the child and family. Informational support and parent educational classes, efficacy of interventions, and having a family-oriented intervention program were also supports for parents.

Being new to the early intervention system. Parents were often unfamiliar with autism and the early intervention system. Adjusting to the autism diagnosis while learning about the early intervention system was challenging for parents at this stage. As Eric said, “when you’re new, […] You don’t know anybody, you don’t know anything. […] you don’t even know necessarily how to help your child.”
Accessing services. Locating and navigating the early intervention services for their child were challenges for Rose and Eric. A family Eric knew with two children with “fairly low functioning” autism were among the first to receive a priority slot for their children in the Registry of Unmet Needs after one and a half years of fighting for their right to a priority slot. As he said, “I know we weren’t the only ones that said, ‘how did you do that?’ Because we didn’t think it could be done.” In addition, agencies were not always forthcoming with information about the services they could provide, which made it difficult for parents to know what was available. The amount of time and effort that had to be put in by parents in just accessing services was also a stressor. As Eric said, it was like a “full time job […] just trying to figure out what services are available and how to use them and how to get through the red tape”.

Service providers: Lack of knowledge and unsupportiveness. Service providers were both a stressor and support. Service providers’ knowledge of autism was critical at the early years. Service providers who did not recognize symptoms related to autism contributed indirectly to parent stress as it meant a later age of diagnosis, as was the case for Sharon’s son, Carl, who was only diagnosed at age 12. In Sadie’s case, the department chair’s failure to recognize hyperlexia and autism provided false hope that the challenging behaviors Sadie’s son, Luke, demonstrated were due to his being a genius. Luke received his autism diagnosis only at age 8. These later diagnoses meant receiving appropriate services later when they may have been more beneficial if provided at an earlier age.

Service providers were also stressors due to their attitudes toward the child or their manner of conveying information to the family. For instance, Sarah “felt like [the speech therapist] was upset with him all the time about his behaviors. But I was kinda like, this is why we’re here. It’s because he has behaviors and we need some help.” As for Grace, her then neurologist’s lack of preparation (not reading Nick’s medical records) prior to their
meeting led her to misunderstand Nick’s behaviors in the clinic. In addition, the lack of forthcoming information during the diagnostic process, such as not keeping parents informed about what their suspicions were, was a stressor for parents since it added to their sense of uncertainty.

**Informational support.** Despite the lack of knowledge and support from some service providers, service providers were nonetheless an important support when providing information about available resources, services, and activities, especially just after diagnosis. For example, just after Sarah received Mark’s diagnosis, his developmental pediatrician “just gave us a whole list of resources and told us exactly what we needed to do. […] So we had somebody right away that told us what to do.” Similarly, Mary received a “swag bag” of “pamphlets, therapy places, or play places, or psychologists” giving her a starting point to search for services and resources.

**Parent education classes and family oriented programs.** At the early childhood stage, parent education classes such as informational sessions or individual problem solving sessions were useful in providing Mary, Sarah, and Joan with a better understanding of autism and equipping them with tools and strategies to use in the home. In addition, parents got to know other parents of children with autism or other disabilities and to build a support network through that (e.g., Sarah and Mary). Rose, Eric, Joan, and John also mentioned retrospectively that programs tended to be more family-centered in the early childhood stage, especially from ages 0 to 3. This was probably in comparison to the fewer supports received when their children entered school-age years and supports became more education-oriented. For instance, Joan recalled when Leroy was a toddler till preschool, they had “a comprehensive kind of support system” encompassing school services, as well as home and community support.
Efficacy of interventions. Both parents in the early childhood category discussed the efficacy of the therapies and treatments as a source of support. For Sarah, despite having several types of therapies, her son’s social behaviors demonstrated significant improvements only after starting ABA therapy. Mark now responds when asked a question, where before he would simply ignore requests. Also, he now participates in his class in church instead of having a tantrum. Mary attributed the “enormous leap of progress” in her daughter’s speech and social behavior primarily to medical interventions. For instance, Alice had been a nonverbal child until they began the medical interventions, when she spoke for the first time. Also, she now watches her peers, even laughing at funny occurrences; whereas before, “it’s just like they were invisible”. Mary also felt like Alice’s personality (e.g., having a sense of humor, being a “willful, sassy little thing”) emerged only after the interventions, which allowed her to know her daughter better – “it’s neat to see that come out because that [personality] was never there [before]”.

Themes in early childhood revolved around child-related issues, parents’ adjustment to the diagnosis, and issues associated with the entry into the early intervention system. Supportive factors at this stage addressed their need for information and strategies to support the child.

Early childhood to middle childhood stages. Most of the themes in middle childhood (approximately ages 8 to 13) were shared with early childhood and will be presented in this section. Themes unique to the middle childhood stage included the escalation or emergence of challenging behaviors, the child’s increased size and intelligence, as well as the support of a community support person. Themes overlapping from early childhood were child-related (e.g., limited functional skills), parent-related (e.g., balancing family and work demands, social isolation), and finance-related (e.g., support from Medicaid or state-funded waivers, stressors from high cost of services and limited insurance coverage).
Factors relating to schools and service providers will also be highlighted here as they appeared to be relevant especially for the early and middle childhood stages, extending sometimes into adolescence.

**Child-related factors.** Child-related factors specific to middle childhood were the escalation or emergence of difficult behaviors and issues related to the child growing and maturing. From early to middle childhood, the child’s limited skills were stressful for parents. However, being able to observe the progress in their skill development was encouraging.

*Escalation or emergence of challenging behaviors.* At the middle childhood stage, the escalation of some difficult behaviors (e.g., aggression, sensory-seeking) or the emergence of new difficult behaviors (e.g., defiance) were challenging for Eric, Rose, and Sharon. For instance, Aiden’s current behavior issue was defiance such as refusing to use the potty despite being 10 years old, and refusing to do his homework. As Rose explained, “So it’s like, okay, how much of a fight are we willing to put up with.”

*Child’s increased size and intelligence.* Another feature specific to middle childhood was the child’s increased size and intelligence. This was a stressor as the child still lacked safety awareness but had more mobility and was more difficult to manage physically. Eric likened it to “an arms race” as his daughter, Lizzy, got “bigger, and smarter, and stronger, taller”, where they had to constantly “stay one step ahead of her on anything that is a safety issue”. When Lizzy was younger and smaller in size, they could carry her during a meltdown. However, now at age 10, they have to coax her out of her meltdowns or give up on original plans to go out.

*Child skills and progress.* The child’s limited functional skills was a stressor for parents (Mary, Rose, and Eric) across early and middle childhood ages since they had to provide constant assistance. As Mary said, “every single part of her day is assisted with.” In addition, communication was an issue for Mary and Eric since their children did not have
sufficient expressive and receptive language. When Eric’s daughter, Lizzy, was sick or upset, “there still is no way, to kind of ask her what hurts or what’s wrong. We can only just guess, take her to the doctor and then they guess.” This was distressing for parents as they were never entirely sure what was troubling their child.

Nonetheless, there were some improvements in child behaviors and skills as the children grew older and matured which meant parents did less behavior management and more of other activities. For instance, Aiden is now less prone to reach for goods in the grocery store and holds his father’s hand instead having to be placed in a stroller. With less challenging behaviors, parents also talked about being able to do more things. Sarah described the progress as going “from a place where he needed attention almost every second of the day that he was with us, to where he’s a little bit more independent and easier to take care of.” As she explained,

it’s nice to get to a point where not only are we not worrying about horrible behaviors, but instead we’re working on saying your name and communicating with us and following directions.

**Parent-related issues.** Across the early and middle childhood years, parents spoke of having to balance between family and work commitments and dealing with the social isolation resulting from having a child with autism.

**Balancing family and work demands.** Sarah, Eric, Rose, and John mentioned difficulties in balancing work and family commitments particularly during the early to middle childhood years. This was possibly because parents were still establishing their careers while taking care of a family with young children. Sarah, whose children are 5 and 7 years old, works full time while her husband, a medical resident, works 78 hours a week. Despite having some flexibility at her work, “when you have to leave work four times a week for an appointment, […] It’s just hard to do”. In addition, the challenge for Eric and Rose lay in needing to work to pay for the therapies, but also needing to care for their children. Eric’s
wife works part time so she can look after their daughter, while Rose’s husband is the sole breadwinner as they cannot afford childcare for their son. When Leroy was in his preschool years, John and Joan also found it challenging to get their children to the various appointments while completing their doctoral studies.

*Social isolation.* Sarah, Mary, Rose, and John raised the issue of social isolation across the early and middle childhood years due to the need to accommodate the child’s needs or behaviors. As Mary noted, there was “a lot of very pragmatic isolation”. Additionally, many families in this study had relocated to a different state at least once. Hence some isolation often accompanied the initial transition to the new state. None of the parents at the time of this study lived near their extended families and thus could not rely much on practical family support.

*Finance-related factors.* Financial support such as Medicaid or state-based programs providing financial waivers, were helpful for parents when made available, and were mentioned particularly with reference to the early through middle childhood years. These financial supports provided parents like Mary, Rose, and Eric with access to services and material needs. For example, Mary’s home assistant was a great help especially since she had a son with disabilities as well. Eric’s daughter, now 10, now has access to respite services and daily out-of-school skill-building programs with additional hours during summer and holidays, all of which they did not have prior to the financial assistance. The financial supports also provided for material needs such as diapers, which was helpful for Rose when Aiden was 4 years old but not yet toilet-trained.

Despite the financial supports available, finances were still a stressor for almost all parents particularly in the early and middle childhood stages due to issues like limited insurance coverage and high cost of services, ineligibility for financial aid, long waitlists, and additional expenses. For example, Sarah’s son, Mark requires weekly speech and
occupational therapy. However health insurance only includes 20 visits each a year and they pay out-of-pocket subsequently. They were also fortunate to have a wealthy relative paying for his ABA therapy, which cost more than her husband’s medical school fees. However, for most parents, the high cost of services coupled with the limited insurance coverage often rendered beneficial services inaccessible. In Mary’s case, being a single parent with two children requiring costly medical interventions, “the lack of money, is always an enormous stressor” as her pension and Medicaid has to cover both household bills and children’s medical and therapy bills.

Ineligibility for particular forms of financial aid was an issue raised by Eric and Rose. Eric’s family did not qualify for low-income aid; Rose’s family did but their income was not low enough and made them still ineligible for additional support. Hence they were caught in the middle by not qualifying for low-income aid and not being wealthy enough to afford out-of-pocket services.

The long waitlist for financial waivers was also frustrating for them, especially relocating to a new state since they had to reapply for state-based financial waivers. Eric recalled when they first applied for the state waiver in 2010, “they wouldn’t tell us […] how far down the list are we. They would just say, […] the person at the top of the list has been waiting since 1998 for services. And so at that point we thought, well, we’re never going to get it because we’re a decade behind on the list.” As Rose said, “It’s like okay, just sitting there, praying it’s before he’s an adult”, and ages-out of the eligibility criteria.

Parents also spoke of additional expenses such as diapers for Aiden, who at age 10 is not yet toilet-trained, and for special equipment or home modifications to accommodate their child’s needs. For example, Eric spent over $1000 on an iPad for Lizzy’s communication skills as they had to get the super-extended three-year warranty, a waterproof case, and the communication apps.
School and service provider-related stressors. Most school-related factors and service-related factors were evident across the school-age stages (early childhood through adolescence) and will be discussed together in this section as most of the themes were more prominent at the preschool to middle school years. The stressors will first be presented. Stressors stemmed from matters such as inconsistent availability of service delivery, school placement and inadequate supports, poor quality of school practices, and negative incidents or abuse cases. Supports related to the school and service providers will be presented subsequently.

Inconsistent service provision. Service delivery was not provided consistently throughout the years due to the service provider leaving, budget cuts, or, in Eric’s case, exiting the 0-3 service provision. Mary described her home assistance in the past few years as “a lot of off and on. […] 40% of the last three years I’ve had some consistent assistance. And the 60% has been not.” The community support hours for Joan and John’s son, Leroy, which had been extremely helpful, had been reduced over the years, from 20 to 4 hours a week, due to state budget cuts. This inconsistency in service delivery often meant parents did not receive the full benefit of the services.

Placement issues and inadequate service provision. The lack of suitable school or class placement options accommodating the child’s academic and social or behavioral needs was a concern for Sarah, Mary, Sharon, and Grace. For example, Sarah had wanted Mark, the only verbal child in his autism class, to spend time in a typically developing pre-k class to improve his verbal and social skills. However, due to licensing restrictions, the school could only offer two options: stay in the autism class, or attend a cross-categorical class held three days a week, with twice the student-teacher ratio. As she said, “So it’s just like I had no good options.”
In addition, school budget issues led to inadequate school supports (e.g., one-on-one aide, adaptive P.E.) for both Sadie and Rose. Sadie had even filed for and won two lawsuits when her son was in an elementary school that had refused to provide federally mandated supports such as adaptive P.E. Despite winning the lawsuits, the certified person for adaptive P.E. was only available at limited times; Luke had to join regular P.E. other times. As Sadie summarized, “legally, I got the services, but I didn’t get the services”. When her son was in middle school, she described the school’s policy as being “always about how little can we provide because we don’t want to pay for this. Had nothing to do with what would benefit Luke.” The middle school’s lack of foresight was evident when Sadie highlighted the importance of providing services and the long-term consequences of not doing so at a school board meeting, “their comment was we aren’t concerned about what happens after high school.” As she noted,

I was looking long-term. They were looking short-term. [...] they only had to deal with [Luke] for one year. And then it became someone else’s problem.

**Poor quality of school practices.** Sarah, Mary, Rose, and Sadie also mentioned general concerns with the quality of the schools. Sarah’s concern was that her son, Mark, was in “one of the lowest performing schools in the district”, which she described as “disorganized” and “overwhelmed”. Mary’s lack of confidence in the state’s public school special education program had led her to homeschool her daughter. Rose cited an example of the elementary school her son had been in:

The more I kept going back to the class that year, I realized that every time I showed up the lights were off in the room, cartoons were playing on the TV. They weren’t really following a schedule. They weren’t really doing anything.

**Negative incidents or cases of abuse.** Across the early childhood, middle childhood, and also adolescence stages, the occurrence of negative incidents or abuse cases was understandably distressing for. While John alluded to bullying incidents in middle and high school, Rose and Sadie had extremely negative experiences from preschool to middle school.
Rose had a series of unfortunate encounters with Aiden’s preschool in terms of abuse incidents (e.g., adult thumbprint bruises lasting weeks), a lack of proper protocol (e.g., losing Aiden on the playground and not informing her till 10 o’clock at night), and the school’s inability to handle her child (e.g., breaking his beltloops in an effort to get him on the school bus). The final incident occurred when an older 200-pound fifth grader bit his face, breaking it in 3 to 4 places, despite there being three adults and only one other boy in the room.

Sadie also recalled several incidents of mistreatment. For instance, Luke disliked wearing shoes due to his sensory issues. However, his elementary school teacher had insisted he keep his shoes on and tied his shoelaces so tightly his feet had welt marks. In middle school, despite knowing “how much food meant to Luke, the teacher had given him his snack last, but told him to put it away as the next lesson was starting:

Everybody else had had 15 minutes to snack but not Luke. He freaked out. I mean freaked out to the point where they called me. And when I went in to get him, he was sitting there surrounded by all of them: the principal, the nurse, the psychologist, the teacher, the whole- white as a ghost and trembling. You have to know [sigh], I took him in my arms, and he just sobbed.

After this final incident, Sadie had moved Luke to a private school, which was paid for by this middle school in order to avoid a lawsuit for abuse.

School and service provider-related supports. Despite the negative experiences parents had, there were supportive factors related to schools and service providers such as knowledgeable and experienced professionals, communication with parents, practical support personnel, parent education courses and suggestions, collaboration among teachers and other professionals, and teachers who cared about their child.

Knowledgeable and experienced professionals and teachers. Professionals who were knowledgeable and understood autism were a great support for parents like Grace and Sadie. For instance, the neurologist for Grace’s son, Nick, was able to determine through a blood test that a caesin-free diet would not work for Nick, which was a good finding since Nick
loves ice-cream. He also realized Nick’s apparent inability to do more than two tasks before being rewarded had more to do with the length of time than the number of tasks. Sadie’s speech therapist, also an expert in hyperlexia, proved a major support. For example, she was the one who finally taught Luke to learn to write in middle school, “because somebody thought outside the box and remembered […] how he did better reading words than he did from understanding verbal communication”.

Similarly, it was important for parents that teachers understood autism and were experienced in handling children with autism. Unfortunately, Sadie and Grace encountered teachers who did not understand children with autism, leading to negative consequences. Sadie was especially angry with the teachers in Luke’s first middle school for insisting he to do things beyond his current capabilities (due to his motor delays), resulting in him expressing behaviors such as fecal smearing. She lamented, “Teachers have such power with your child that they can make them a behavior problem. All of the careful intervention I had done with Luke […] they refused to do. They figured he just had to be sat on.” Grace recalled her frustration when her then fourth grade son’s teacher did not understand that timeout alone in a room was a reward rather than a punishment for aggressive behavior, especially since Nick enjoyed telling himself stories.

Conversely, parents were pleased when teachers understood autism and their child as it not only meant they knew how to handle the child appropriately, but parents were also assured of their child being in safe and good hands. As Eric said, knowing that the school was “working with [Lizzy] every day on building her skills” and having assurance that for “however many hours a day that we know she’s safe, and we know she’s learning, and people are caring for her” was a support. Sadie described her delight and relief when Luke started at a middle school for children with disabilities that had qualified staff who “got it”:

they understand that every kid is different, especially every kid with special needs and they are willing to do what it takes to make things work.
Communication with parents. Communication was one of the key factors influencing parents’ experiences with schools. Communication was important as it kept parents informed of their child’s progress and of incidents in school that could affect the child’s behavior at home. Sarah, Rose, and Sadie had been displeased with the lack of parent-communication in some of their children’s schools across the preschool to middle school levels. Rose recalled her distress upon realizing that her son’s previous elementary school had not informed her when the 200-pound fifth grader accidentally hit her then 45-pound son during a meltdown. She only found out later on from her target case manager who had been at the school. This was an issue as had Aiden subsequently been unwell at home, she would not have known why.

After these negative experiences, Rose and Sadie expressed relief when their sons started in schools that kept parents informed of what happened during the day. For most parents, communication occurred through phone calls, emails, meetings, conferences, notebooks (e.g., Eric), or picture books (e.g., Joan) where the teacher or school therapist sent information home to the parent and parents could respond. Leroy’s first grade teacher would even record her instructional sessions with Leroy and send it to Joan and John.

Practical support from professionals. From the early to middle childhood ages, one type of service provider support parents found most helpful was the practical support they offered such as having home or community assistance, and respite services. As Mary, Eric, and Rose noted, having an additional person to help care for the children was a support. For instance, the home assistance allowed Mary, who had two children with multiple disabilities, a “one-on-one defense” where she could attend to one child while the home assistant attended to the other. As she said, “I don’t think I would be making as much progress with them without the assistance I’ve received.”
Community assistance was a crucial support for Grace, Joan, and John in helping their child engage with the community, especially in middle childhood. For instance, Joan and John were thankful for Connor, Leroy’s community support person from elementary to middle school, who brought Leroy out to the community (e.g., malls) and provided “real-time, on-site” support and advice in negotiating situations (e.g., returning items). John also appreciated that Connor was a non-parental figure, closer to Leroy in age, whom they trusted to support Leroy and also “gave us a break from having to do all these things ourselves”.

Respite services were useful for Mary, Rose, and Eric in providing some downtime, time for other activities or household errands, or time with the other members of the family. As Eric said,

> It’s not necessarily that you’re going to go out to the movies or to dinner or something. It’s more like there’s just somebody there at the house […] Not working on learning necessarily, more just someone there. And that way you can, […] go pay your bills in the other room or you can go do something with the boys who are, you know, there’s places that you just can’t take Lizzy that the boys would like to go to.

*Parent education courses and suggestions.* Schools were not only a support when they themselves were equipped, but also when they equipped parents through suggestions or parent education courses. For instance, Joan spoke of Leroy’s preschool which “made it a point to educate parents” by providing access to conferences and parent training courses. Suggestions from school staff and therapists were helpful for parents, especially during the earlier years, when parents were either new to parenting or new to having a child with a disability. For instance, the learning specialist working with Leroy, Joan’s son, also worked with the parents to “help us get to better know how he best learns and how to support him”. This was useful for them as she explained, “Leroy is our firstborn. So we were new to parenting. And then on top of that to have a child whose development was different from what we expected.” The suggestions addressed different issues from simple tasks like sitting Grace’s son in an armed chair to stop him from getting up, to pre-empting future concerns.
For example, Joan and John’s doctor suggested letting their three older sons become certified babysitters. Sadie’s therapist recommended enrolling Luke in a high school where he could be part of the community post-graduation, although it meant losing Luke as a client.

_Collaboration among teachers and other professionals._ Rose and Sharon noted that having service providers and teachers who collaborated with each other was a help as they kept each other informed of the child’s needs and progress. For instance, the learning specialist working with Carl when he was in middle school kept his teachers informed about his needs. Hence they were more understanding and able to accommodate him.

_Teachers who cared._ Ultimately, what mattered to parents (John, Joan, and Sadie) was that teachers cared about their child. For example, even though Sadie had had issues with Luke’s elementary school on adaptive P.E. and inclusion issues, she was “relatively happy about his placement” because he had “teachers who cared about him”.

While the themes in middle childhood tended to overlap with those in early childhood, with greater focus on obtaining supports from schools and service providers, themes in the next section, adolescence, were more related to preparations for transition out of school.

**Adolescence stage.** Adolescence (approximately ages 14 to 19) was marked by particular child-related stressors like the child’s limited social skills, need to learn independence, and larger physical size, as well as school-related transition issues. Preparation for independence was a key theme for this stage as the adolescent would age-out of school services in a few years. Parents at this stage were also concerned about what was next for their child and found informational supports about transition and guardianship helpful. Other themes in adolescence relating to independence and future concerns overlapped with adulthood and will be discussed further in the adulthood section.
**Child-related stressors.** Child-related stressors at the adolescence stage were limited social skills, challenging behaviors, larger physical size, and concerns for independence. These issues were concerns for parents due to the implications of their adolescent’s ability to transition to adulthood, which was a key theme at the adolescence stage.

*Adolescent’s limited social skills.* Both Leroy and Carl have limited social skills, which was difficult for their parents to observe when it affected their ability to create and maintain friendships. By adolescence, the social issues became increasingly salient since parents were no longer able create the social opportunities they might have done when their child was younger. Sharon described her dilemma as such,

> I think the social issues are getting way more pronounced. He moved from being a kid where your parents create social opportunities for you to being more of a young adult where you have to create your own social structure.

*Challenging behaviors.* Some difficult behaviors were still present during adolescence such as Carl’s fixation with routines and his oppositional nature, and Leroy’s sleep disturbances and tendency to perseverate about upsetting situations. Carl’s need for routine meant Sharon still had to remind him a few days in advance of appointments he had or he would get upset. Leroy still had sleep disturbances every few weeks, with each occurrence lasting up to two weeks. Hence he tended to be tired during the day and his parents, both university professors, were “even more sleep-deprived than we typically are”. In addition, Leroy’s tendency to perseverate, for instance when he thought a peer had mocked him, would upset him. Instead of having meltdowns now however, he would brood over an issue for weeks. Hence the challenge for his parents lay in trying to comfort him and redirect his thoughts.

*Adolescent’s larger size.* At this stage, the adolescent’s physically larger size was more of a safety concern for the parent since there was a danger of the adolescent hurting the parent. For example, Nick’s larger size was a concern for his mother Grace because there was
a possibility of her getting physically hurt, especially as she was a single mother and was
often alone with him—“if I couldn’t get his behaviors under control, there was a real fear that
he could hurt me.”

Concerns for independence. At this stage, parents were becoming concerned about
their adolescent’s ability to function independently. For instance, Joan’s son, Leroy, still had
difficulties understanding the importance of being on time and managing his money, both of
which are important work-skills. Carl’s ability to manage his epilepsy medications, which
were constantly being adjusted, was a concern for Sharon. In fact, a few weeks prior to the
interview, Carl had been admitted to the emergency room because he had taken an incorrect
dosage of his medication. With adulthood drawing near, parents felt a pressure to help their
child become independent and prepared for work. This was stressful as they were not always
sure how to help him or if the schools would be able to help. As Joan said,

I don’t know if that’s [the issue of functional independence] something that can be
addressed… in the schools. And because we don’t have any other resources, it puts
that weight on us to ensure that it happens. And I just don’t know how to make it
happen.

Sharon also talked about the stress of transition planning and the high stakes involved since it
impacted the rest of Carl’s life,

The stakes are really high. You have, you know, what is his life going to be like. […] We
don’t want him to live with mom and dad for the rest of his life, you know. So we
want to do our best to try to help him achieve the most he can achieve.

School support in transition planning. At this stage, the school was, in Sharon’s
words, the “base” for transition planning. Hence, when transition planning was not
adequately conducted, parents had to search for adult supports on their own for a new phase
of early intervention that they were unfamiliar with. Added to this was the stress of knowing
their child would age-out of the current school services in a few years. For instance, Joan
spoke of the “more pressing” need for non-school-based, community supports for when her
son, now 16, aged-out of his current school services. Sharon was in the process of planning
transition for her 17-year-old son, Carl. However, the school’s unawareness of services such as the vocational rehabilitation services (VRS) was a disappointment, as she felt “I shouldn’t have found that [the VRS] myself. The school should have pointed me to that.” To their credit the school was willing to work with the VRS and even arranged for a VRS personnel to come to the school so they could learn more about the VRS.

**Parent education courses.** For Sharon, the parent education classes and webinars organized by external autism organizations provided her with knowledge on issues related to the transition from adolescence to adulthood, such as the VRS and guardianship matters, which were relevant for her son who was approaching his final year in school. Through the courses, she also learned to be “more of an advocate for him at school, being a little bit more vocal about […] helping him be successful at school”.

In general, themes in the adolescence stage were related to the adolescent’s skills and larger size, as well as concerns for his ability to be independent. Parents also had concerns with school support in transition planning as it was crucial at this stage. Parent education courses providing transition-specific information were key supports as they facilitated parent knowledge about the transition to adulthood. Themes in adulthood will be discussed next.

**Adulthood stage.** Key themes in adulthood overlapping with adolescence included the actual transition to working life and the availability of supports for adults with autism. Specific to the adulthood stage was the parents’ preparation for the child’s future after their deaths.

**Transition from high school to employment.** The transition into employment was challenging for parents as their young adult had limited functional skills necessary for maintaining employment and for independent living, which made the search for a suitable job difficult. For instance, Grace still manages Nick’s finances because,
if I gave him all of his money and said you need to take so much out to pay for your for rent, and you need so much for food and so much for your phone or your lights or Internet, I don't think he could manage that.

Sadie’s son, Luke, had wandering issues and could not work in an open environment because he would get distracted and walk off his job site. He also was unable to work in a sheltered workshop as he needed the freedom to move around. Hence the organization helping with the job search found it difficult to find a job fitting Luke’s abilities while accommodating his wandering tendencies. As Sadie exclaimed, “it literally took an entire year to find a placement that would fit Luke.” What was challenging for Sadie was figuring out what Luke could do during the job search:

Because if Luke was left to his own devices during the day, […] by the time you come home at night from work, he is so OCD, he is like a spinning top. He’s been on the computer talking to himself all day.

**Limited adult supports.** Although the need for information on resources and services and not knowing what was available was stressful for parents across all stages, it was especially salient for parents due to the limited adult supports and services. When researching adult services for her 17-year-old son, Sharon felt like she was “doing it on my own” because the school did not provide sufficient information, and she was unaware of what supports existed for adults. Sadie, whose son is already 23 was still frustrated with the lack of adult supports available. As she said,

once you have an adult, there’s nothing. […] They focus all on school-age. […] It all stops at age 17. And the need doesn’t stop.

What made it challenging for Sadie was the “big split between abilities” in services and programs available. Since her son fell in the middle range, he was not able to actively participate in activities for individuals who were higher functioning, and was not stimulated by activities catered to those who were lower functioning:

You’ve got the kids who are in group homes, with one-to-ones. Wheelchair, MS, all those things. Then you’ve got the kids who are high functioning. And there was nothing in the middle.
Preparations for the future. A key theme of adulthood was the parents’ need to prepare for the child’s future after their deaths. For Sadie, since they have yet to find a guardian for Luke, and both she and Sam are getting older, there is a pressure to help him become as independent as possible. She phrased it this way,

the clock is ticking now in a different way. Before I had this mental thing about that 15-year-old deadline where everybody said this is where they stop progressing. Now I’m thinking of my 70-year-old deadline. […] I have this 10-year picture in my head in terms of we have to get him as independent as possible […] I’ve got a 10-year window to get him there.

However, she has had a special needs trust fund set up for Luke so her main concern is not for his physical needs, but that he will lack emotional support. As she explained,

What he will lack for, possibly, is affection, and love, and caring. And that’s something you can’t buy. So my big stressor now is what happens when we die.

Themes Common Across All Stages

The themes covered in the above sections consisted of themes specific to particular stages. There were also several themes that overlapped across the stages or were not stage-related. These included factors relating to formal supports such as service providers and being in a resource-rich location. The majority of the themes shared across stages were various stressors and supports relating to the child (need to be taught everything, constant worrying), parent (emotional state, older age and health, other supports), immediate family (spouse, siblings, multiple children with disabilities), extended family, friends and parents of children with autism or other disabilities. Parents also discussed internal strengths of the child and parent as key sources of support.

Service providers who were more than just paid staff. Joan and John, Mary, and Grace spoke of the close relations their service providers had established with their family and child. In fact, both Mary’s weekday and weekend assistants had developed close relationships with her family, to the point that their families spend time together, and her weekday assistant was “very much a part of this family”. For John, their community
assistance person was “someone you can trust, someone you feel comfortable with to help your child, provide guidance, provide a social outlet” who remained in contact with them even after moving to another state. At the present stage, Nick’s three care providers are a source of support for Nick and Grace. As she explained,

they spend their work hours with him. But they also choose to spend additional time. [...] they’re more than just his paid staff.

Resource-rich location. Being in locations where resources were readily available was a support for several families. For Joan, the first state she was in had provided comprehensive family-centered services, which she found tremendously helpful. For Mary, Sarah, Sharon, Grace, and Sadie, the autism-related resources available in this Southeastern state were a support. An example of such resources are the various organizations working actively with and for families of individuals with autism, providing parents with access to autism-related resources, workshops, and activities. In fact, for Mary, Grace, and Sadie, it was the primary reason they had relocated here.

Child-related factors. Across ages, parents also discussed child-related concerns related to their need to be taught everything, and having a constant worry not just for their child’s future, but at the present moment.

Need to be taught everything. Mary, Grace, and Sadie talked about the need to teach their child things step by step even until adulthood, which was time-consuming and a challenge especially when it involved the child’s safety or they had other chores. As Mary said, “there’s not a lot of intuitive learning going on at all”. Grace also explained the need to not “take for granted” that their child understood the dangers of crossing a street or opening the doors to strangers. She gave an example of how they had not realized that Nick as a young adult still had not understood the latter:

when he said ‘who’s there’ and the guy yelled ‘UPS’ and he opened the door. And I said, ‘Nick do you know who UPS is?’ And he said no. And I said, ‘why’d you open
the door?’ He said, ‘he told me who he was’. So you can’t make those […] Assumptions or those leaps for the next part. Everything needs to be put out there.

Apart from safety issues, Sadie wanted Luke, now 23, to continue mastering job and life skills. Hence she still had him clean the house with her. However, correcting his mistakes also meant it took them “three times as long” to complete the task, delaying her other chores like getting dinner.

**Constant worry for child.** All parents talked about having a constant worry for their child in the present moment. For example, John commented that while trying to help his adolescent son fulfill his desire for greater independence and getting him the appropriate training and experience in driving, they were also “trying not to worry about every potential bad thing that could happen when they’re out there”. As Mary put it,

> all the time there’s fear […] because they’re just more vulnerable people. […] All children are vulnerable […]. But it is different when they have developmental disabilities.

**Parent-related factors.** Parents mentioned having negative emotions throughout the years of caring for their child and also had aging concerns. However, they also found different kinds of supports (e.g., therapists) or outlets (e.g., smoking) helping them to cope with the stressors.

**Emotional state.** Mary, Sarah, Rose, and Sadie spoke of having depression, anxiety, and fear at the beginning when they realized their child had autism, and over the years, even up to the present moment. Rose’s high stress levels led her to resort to smoking as an outlet. Sadie’s negative experience with the school system from preschool to middle school resulted in her being in a constant state of “fight or flight”, which culminated in a bout of depression when her son was 15, and also leading her to cut herself when Luke was in high school.

**Parent health and older age.** Parent health and older age were also concerns some parents raised. For instance, Rose realized she was unable to do as much as she had a few years before, while running on so little sleep and energy. Mary was medically retired from
the navy because of a broken back. A month prior to the interview, she had also been badly injured in a car accident. She was the only parent who indicated her health status as “fair”.

**Other parent-related supports.** Parents also mentioned forms of support that were not specific to any life cycle stage. For instance, Sharon, currently a housewife, was thankful she now had the time to research services that would be beneficial for Carl. As mentioned earlier, Rose’s ‘vice’, smoking, was a stress reliever. Similarly, Sadie took antidepressants and met with counselors who were her “sounding board” and were the ones who said, “There, there. It’s okay.” She had felt partially responsible for Luke’s autism and her self-cutting incident that led to her being in the hospital’s psychiatric unit “alleviated my guilt a little bit because I thought, I failed Luke. I punished myself.” For her, too, work was a form of respite, as she said, “I work for fun. Work is my respite actually right now”.

**Immediate family.** The immediate family (spouse and other children) was both a source of stress and support. In addition, having multiple demands on the parent led to a lack of family time. However, families learned to adjust and accommodate the child with autism.

**Spouse.** For Sarah, Eric, Joan, John, and Sharon, their spouse was a form of support in terms of being, in Sharon’s words, an “active partner” in helping to care for the child. For instance, Eric’s wife made onesies with zippers in the back for Lizzy, who was already 10, in order to prevent Lizzy from removing her clothes at night together with her soiled diaper. Sarah felt her “strong marriage” was a big support.

For Grace and Sadie, their husbands (or ex-husband, in Grace’s case) were both a support and a stressor. Their husbands had been helpful in providing practical assistance such as bringing the child out so they could do other things. However, their lack of understanding and ability to deal with a child with autism contributed to Grace and Sadie’s stress. For instance, Grace’s ex-husband developed hiccups when her son was hospitalized for pyloric stenosis at six weeks old. However, instead of being more concerned for his son, “every time
a group of interns would come in, he would want a cure for his hiccups”. The situation was somewhat different for Sadie as she and Sam had stayed together because of Luke. But when Luke’s disability became evident around age 4, Sam had initially “disengaged himself from the fact that Luke had a disability”, leaving Sadie alone to deal with “the escalating issues that were becoming apparent with Luke’s disability.” At the present stage, Sam has been increasingly more of a stressor than support due to his inability to look out for Luke. Sadie recalled a recent incident when Sam had been unaware of Luke having a seizure in the next room:

Sam was like, ‘What?’ I’m like, ‘Are you serious?! Didn’t you hear him choking in here?!!’ ‘What?’ So Sam.. it’s like I’ve got one ear wherever Luke is, and one ear on what I’m doing. Sam is like oblivious.

Thus, although Sam worked from home, his lack of attentiveness to Luke’s symptoms led Sadie to reduce her work hours so she could stay at home instead to help care for Luke.

**Having multiple children in the family.** All families except Sadie’s have more than one child, and two families have another child with a disability. Hence they had to manage between meeting the needs of their child with ASD, as well as those of their other children. This was challenging in terms of the amount of financial and material resources they could devote to their child with ASD, while still providing sufficient time and love for the other children. When Rose gave an example of having to deny Celine’s desire to join the cheerleading squad due to their limited funds, she concluded, “it’s so hard to say that to a child.” As John summarized, “you have to be concerned about everybody. So we can’t just put all our resources with Leroy.”

However, having multiple children also meant siblings, regardless of birth order, who were mature enough could provide general help such as cleaning up messes or keeping an eye on the child with autism, allowing parents to attend to other matters. For instance, Rose can now answer the door or go to the bathroom while 7-year-old Celine keeps an eye out for her
10-year-old brother, Aiden. Siblings also provided a form of social group for the child. Mary was very grateful for Alice’s brother because, “the only time we’ve ever seen real peer play happen with Alice, is her brother.” Even at the adolescence stage, siblings appeared to form the adolescent’s main peer group.

Apart from general help and social support, Eric and Joan’s children were also advocates for their sibling with autism. For instance, Joan’s second oldest son was “more protective of Leroy especially when they’re in environments where he feels like Leroy is being misread”. Eric and Grace also found assurance in knowing the siblings would be a future support for the child with autism. As Eric noted, “I’m glad we have two sons, not one, to just increase the support she’ll have as an adult.” Grace was the only parent who did not talk about worry for the child’s future as James, Nick’s older brother, had “agreed to be his guardian, and take care of him when I’m not here anymore”. James’ commitment to Nick was evident in his comment “we’re a package deal. If she doesn’t get Nick, then she doesn’t really get me.”

**Having more than one child with a disability.** Mary and Grace both had two children with disabilities. Grace did not talk much about having multiple children with a disability, possibly because her older son has a higher functioning form of autism, and was holding a stable job. Also, the conversation was focused on Nick and she appeared content with their current situation. However, both Mary’s children have moderate to severe autism and medical complications – her son had a stroke at birth and has mitochondrial disease and cerebral foliate deficiency. Hence, as she said:

> I have a very different parenting experience here. […] I don’t have a neurotypical child. I have two children that would end up having very, very complex special needs. So I’m just going through a very different parenting experience with different goals and different expectations.

**Lack of family time.** Multiple demands from work, the child, and other family members also led to a lack of family time which, as Sarah said,
just felt miserable because we’d come home from work and it was like, we didn’t have any family time because we’d have to be helping him try to calm down and not throw a tantrum.

Eric also explained that costs involved in finding one or two babysitters who could handle Lizzy and their other sons made going out cost-prohibitive – “by the time you pay for all that and then go get dinner, you’re out 150 bucks or something.”

**Family adaptation and accommodation.** Sarah, Mary, Eric, and Sharon also spoke of family strengths, including learning to adapt to and accommodate the needs of the individual with autism and communicating among family members. For example, Sarah explains, “some things we know not to, we just know, like if you have to be quiet, or if they’re going to have lots of [inaudible] lights or it’s going to be loud, we’re just not going to do go do that. And so part of it is us readjusting”. As Mary put it succinctly, “We have learned how to survive.”

Joan, John, and Grace also mentioned having open communication with the different members of the family to address concerns. For example, Joan and John have talks with their sons about, “in house, this is what’s going on with Leroy or these are some of the ways you guys can help. Or whenever they have feelings about whatever’s going on”.

**Extended family factors.** Apart from the stressors and supports associated with the immediate family, a few parents also cited different members of their extended families as both stressors and supports. Most families lived away from extended family (i.e., in-laws or own parents) at the time of the study, hence their extended family was not often mentioned. For those who did, the extended family often provided child care, financial help, or emotional support. For instance, when Rose had a miscarriage, although her parents were divorced, her mother, paternal aunt, and paternal grandmother drove 4 hours to help take care of her and Aiden. Emotional support was important and did not necessarily focus on the child, but as Sadie said of her sister who currently lives with them, “still, it’s nice to have somebody else
to talk to.” Acceptance of the child by members of the extended family was also a support for Sadie and John. As John explained, the times they visited their extended family was:

a chance for [Leroy] to be accepted without a lot of judgment or modifications […] And so it’s nice for him and for us because we get a chance to not have those additional parenting and logistical kinds of thing.

Despite the general supports from the extended family, Rose and Sadie had issues with certain members of their extended family. Rose had an especially challenging time with her in-laws during her miscarriage. Her in-laws lived 15 minutes away but offered little practical help compared to her mother, aunt, and grandma, who drove 4 hours to care for her and Aiden, who was then three. Sadie’s extended family had been a major source of disappointment when none consented to be a guardian for her only son – “That was a real slap in the face […] My son [pause] who is the most important thing on earth to me, and they said no.” Luke is now 23 years old and they still have not found a guardian for him. Sadie’s fear for her son’s future due to the lack of support from her extended family was a huge source of stress. As she said, “That’s huge. I lay awake at night sometimes and I think about what’s going to happen my son.”

Friends and parents of children with autism. Similar to the support from extended family, friends were a key support for parents in terms of the practical and emotional support they offered, even if they did not have a child with a disability. The nature of the supports changed according to the developmental stage of the child. At the younger stages, practical help for Mary, Sarah, John, and Sharon included babysitting, taking a child to and from appointments, or just taking the child out for activities. Friends who had children of similar ages also provided same-age playmates for the focal child. For example, Sarah’s neighbors, who had children of similar ages, would “swap babysitting” so “everybody gets a chance to have a break”. Parents were particularly appreciative of friends who also had children with autism or other disabilities because they could empathize and could exchange advice,
information, and resources. For example, Grace recalled when Nick was younger, the parents had formed a “babysitting coop”, which was a help because “other parents of kids with autism are your best care providers. They understand, they get it, nothing really riles them.”

**Societal lack of understanding.** Societal lack of understanding of autism and of the child with autism appeared to contribute to parents’ stress across the years, albeit in various ways. For John, the lack of acceptance from his child’s peers was difficult for him to observe as a parent. In addition, since Leroy is now conscious that he is viewed differently by others, John also needs to help him learn to be comfortable with who he is and to not let it affect him negatively. In addition, Grace observed that because children with autism may look like typically developing children, people are less understanding of their challenging behaviors. She explained how, when Nick was very young, they had lived in a small town where,

people just didn’t really get it. […] kids with autism, they look so normal […] when people look at him, and he looks normal, and they think, ‘what a spoiled brat’.

**Internal supports.** Internal sources of strengths were intrinsic qualities the child and parent possessed helping them to deal with challenges that came their way. The child’s resilience in dealing with the difficulties associated with their symptoms was an encouragement for parents. Parent strengths were crucial supports that helped parents press on during the journey of caring for their child across the life cycle stages.

**Child resilience.** Joan, John, and Sharon found encouragement in their sons’ resilience and persistence in the face of difficulties in social interactions and handling medical complications. As Joan said,

I’m always impressed by his resilience to just continue on even when things are really difficult and it seems that people don’t really appreciate him for who he is […] it doesn’t dampen his spirit. I mean he recognizes it. But he continues despite it.

Apart from his social difficulties, Carl also had to deal with daily medications for his epilepsy and periodic EEG tests where a device is wired to him for 48 hours. Sharon noted,
he has to put up with a lot of things and I think, he may not recognize it in himself. But I think he is pretty strong to have to deal with some of the things that he is going through.

In addition to their child’s resilience, which appeared to contribute to parent’s support, they also described several personal strengths that helped them in the journey of caring for their child and family. Key themes include having realistic expectations and being accepting of your child, fighting for your child, doing all you can, having determination, perseverance, and hope, showing initiative and resourcefulness, having prior knowledge or experience, early planning, raising awareness, possessing a sense of parenting self-efficacy, maintaining an attitude of appreciation, and keeping a positive outlook.

**Being realistic and accepting of the child.** Maintaining realistic expectations for their child and being accepting of their child’s abilities, strengths, and limitations was an important source of strength for all parents. These included not setting unrealistic goals (Sadie and Grace), being understanding of the child’s behaviors and reactions (Rose and Sharon), and accepting their child as he/she is.

**Fighting for your child.** Mary, Eric, Sharon, Grace, and Sadie also highlighted incidents where they had to fight for their child in the face of difficulties or opposition in getting formal services or appropriate placements from the school or other service delivery agencies and financial waivers from the state. For example, Sadie described her fight for federally mandated services from the school,

> I threw myself into this with both feet. I know the DSM-IV backwards and forwards. I knew state law. I knew federal law. […] they couldn’t tell me anything that I didn’t already know about the law. […] it was like a contest, because they were used to dealing with parents who were not informed and who would back off. And I was neither of those.

**Doing all you can.** Through the stories parents shared, it was also evident that all of them were doing everything they could to the best of their abilities, because, as Mary put it, “there is no other way. It’s not like I am going to give up my kids”. This included finding all
the services and resources they could, working with the child on their skills and behaviors, fighting for their child’s rights, safe-proofing the home to fit their child’s needs, reducing work hours, or making personal sacrifices for their child, such as Sadie and Sam’s staying together despite their marital issues, and so on. As Grace summed it up, “anything I could get my hands on to try to help him, I would do.”

**Determination, perseverance, and hope.** The qualities of determination, perseverance, and hope helped parents persist in their journey of caring for their children. As Mary said, there was an “internal determination” to help her children as much as possible. Parents also talked about having hope for their child, in terms of progressing beyond where he/she is at the moment and having a good future.

**Showing initiative and resourcefulness.** All parents also demonstrated initiative and were proactive in their search for information and resources for the children. For example, Mary became a licensed homeschooler because Alice was unable to cope with the social demands of preschool and elementary school. She also started a playgroup when her children were toddlers in order to meet with other families. Research was one activity that all parents talked about having to do. Several of them had in fact come to this Southeastern state because they had researched locations with good resources for families with autism. All parents had also made efforts to educate themselves from diagnosis to the present time, through studying about autism and attending worships and conferences. Mary even kept herself updated on the latest medical advances because of the medical complications her children have.

**Prior knowledge or experience.** Having prior knowledge or experience with autism and disabilities in general had been a support for Mary as she knew prior to diagnosis that “things were going wrong”. In addition because she had past experience with Alan’s autism diagnosis, she was aware that Alice could have the same diagnosis. The latter was similar for
Sarah, who had relatives with higher functioning autism, and tried to be “attuned to looking for developmental issues” in both her sons.

**Early planning.** Early planning was a strength raised by Eric and Joan in terms of preparing the siblings to advocate or to support the child with autism. Joan stated that they had been “very intentional in trying to train [her other sons] to be advocates”. For instance, her second son sits in IEP meetings to express his concerns on how Leroy is treated and provide suggestions. For Grace and Sadie, early planning was in the form of making plans for their child’s future. Sadie has had a special needs trust set up for Luke; Grace has discussed with her older son about guardianship for Nick. As Grace explained, “If you start talking to your children about sex before they’re ready to have sex. It doesn’t make it such a big deal.”

**Raising awareness.** Mary and John both talked about raising awareness among the people they or their children interacted with so that, as Mary put it, “they understand her and try and include her anyway”. John explained that he and Joan “feel like it’s best to just keep people informed, our child has this diagnosis and what that means is this. [laugh] And he is still a cool kid, […] And this is not all he is.”

**Parenting self-efficacy.** Three parents, Mary, Grace, and Sadie also expressed self-efficacy in their parenting skills giving them confidence in handling challenges and providing assurance that they were doing the best they could. As Mary phrased it,

maybe I really was supposed to be their mother, because I don’t know of a lot of people that could do this. And I’m not saying I do it great every day because I don’t. […] But I do also think I am a very good parent to them.

**Having an attitude of appreciation.** Parents also expressed appreciative and thankfulness for the experiences they had or are having, and spoke of learning to celebrate every progress made. As Mary said,

there’s a lot of reward in this life even though it’s very different parenting experience, […] which I think honestly I feel lucky for that. I don’t think other parents get that […] it’s just taken for granted because that’s normal child development and they don’t get to kinda see it in slow motion in the way we do.
For these parents, every milestone their child achieved was a cause for celebration, providing encouragement for parents and hope for their child’s ability to continue progressing in his/her development.

**Keeping a positive outlook.** Keeping a sense of humor and being optimistic were qualities mentioned by Mary, Sarah, Rose, Joan, and Sadie. As Sadie explained, “you have to have a sense of humor still. […] Because sometimes if you don’t laugh at it, it just, it really gets you down.” Grace also expressed contentment with the current situation when asked if she could think of improvements or things that would provide more support: “I have a good group of friends. We are busy, we have a full life. I don’t think I need anything other than what I have.” In addition, parents talked about viewing their experiences as being different rather than bad. Eric and Grace also cited the story of planning a trip to Holland but ending up in Italy as an example. As John said, it was about accepting the difference and “realizing that this is not the sum total of Leroy or our family experience. […] there’s other stuff that’s happening that’s good and fine.”

It is evident from this study that parents of individuals with moderate-severe autism encounter many challenges across the life cycle of the child. These challenges were related to the child (e.g., challenging behaviors, limited social and functional skills), the parent themselves (e.g., reaction to diagnosis, balancing work and family commitments, worry for child’s future), extended family or friends (i.e., lack of understanding, or unwillingness to help) or the school and service provider (e.g., willingness and ability to support child with autism). Transitions at the adolescence and adulthood stages were also key challenges faced by parents due to inadequate support and limited adult supports available.

Challenges from early childhood revolved around the diagnostic process and parents’ response and subsequent adjustment to the diagnosis, as well as the family’s entry into the early intervention system. Other challenges extending from early childhood to middle
childhood included the child’s escalating behaviors and limited communication skills, parent’s need to balance family and work commitments, financial concerns and the school and service provider’s knowledge of autism, ability, and willingness to support their child.

However, these very sources of stress were also sources of support for parents, both through formal and informal avenues. Formal supports provided through the school and service providers included informational and practical support such as helping parents understand autism and equipping them with tools and strategies for supporting their child, or providing respite services. Informal supports provided through immediate and extended family members, friends, and other parents of children with autism gave parents practical help (e.g., baby-sitting) and emotional support (e.g., lending listening ear). Especially of importance were the child and parents’ internal strengths in helping them throughout the journey of caring for their child. The next chapter will highlight and discuss key themes that have implications for future research and practice.
CHAPTER 5: DISCUSSION

The purpose of this study was to explore the stressors and supports parents of individuals with moderate-severe autism experience across their child’s life cycle stages. More specifically, this study sought to examine the challenges and supports specific to each life cycle stage. It also aimed to understand the stressors and supports that overlap across the stages and how they evolved over time. In depth interviews were conducted with eight families (nine parents) of an individual with ASD about their parenting experiences from their child’s early childhood to the adult life cycle stage. Key themes of stressors and supports were categorized according to the child’s life cycle stages.

Early childhood themes revolved around the child’s diagnosis and the family’s emotional adjustment to the diagnosis and entry into the early intervention system. Receiving the diagnosis was devastating and parents went through a grieving process (DeMarle & le Roux, 2001) regardless of whether parents had suspicions of their child having autism prior to the diagnosis. However, some parents did experience a sense of relief as the diagnosis helped them understand their child’s behaviors and provided formal supports. The extent to which families felt supported was associated with service providers’ ability to provide informational support and connect the family to appropriate resources, which were key features following diagnosis that have been most useful for parents in the literature (e.g., Moh & Magiati, 2012).

Themes in middle childhood were an extension of the family’s adjustment to the child’s development and skills, and the emergence of difficult behaviors. More salient issues across the early childhood and middle childhood stages were financial issues, and stressors and supports from schools and service providers, which sometimes continued into
adolescence. Although higher income levels have been associated with lower stress levels (Orsmond et al., 2007), parents in this study mentioned finance as a stressor regardless of their income levels due to the high costs of therapies coupled with limited insurance coverage. School-age factors such as the teacher’s knowledge of autism, ability to work the child, and willingness to collaborate with the family, and intervention efficacy of service providers were crucial supports for parents across the early and middle childhood stages.

Apart from the continuation of school and service provider-related themes from middle childhood, the adolescence stage was marked with transition concerns as parents made preparations for their child’s exit from the school system and into young adulthood. Parents at this stage required information regarding the resources and supports available in the new phase their adolescent would be entering. However, issues such as the child’s larger size, limited social skills and lack of independence were key concerns for parents as they had implications for the adolescent’s ability to transition successfully to adulthood.

Preparation for employment and the search for adult services continued into young adulthood where key issues overlapping from adolescence included the actual transition from to adulthood and the continued search for adult supports. Parents of these adults also had some concerns and engaged in efforts to ensure guardianship for their adult child after they were deceased.

Themes common to all stages focused primarily on informal supports although they included formal supports like service providers who were more than just paid staff and resource-rich locations. Factors related to informal supports included child-related stressors and practical and emotional supports from the immediate and extended family and friends. Parents also demonstrated internal strengths that helped them throughout the ages.

The following section will discuss the relevance of key themes pertaining to the different life cycle stages and how they support or deviate from findings in existing literature.
The chapter will then conclude with a discussion of the limitations of this study, directions for future research, and implications for practice.

**Early Childhood (Approximately Ages 0 to 7)**

Early childhood themes of stress and support focused primarily on the child’s diagnosis and the family’s reaction and adjustment to the implications of the diagnosis. Parents were understandably distressed by the behavioral and social symptoms displayed by the child, such as challenging behaviors and limited social skills. This was especially so if the child regressed in their development, such as a loss or halt in language and motor skills development. Several studies have documented the impact of challenging behaviors on parental stress (e.g., Davis & Carter, 2008; Estes et al., 2013), which appear to be supported by the findings in this study. As Estes et al. (2013) found, higher levels of parental stress was associated with child problem behaviors. The impact of the child’s challenging behaviors and impaired skill development was compounded by the fact that at this early stage, parents often had little parenting experience and had limited knowledge about autism. Hence, the need for informational support was crucial at this stage.

**Late or deferred diagnosis.** Dismissal of parents’ suspicions or a misdiagnosis by professionals delays the possibility of receiving appropriate interventions (Neely et al., 2012). Sadie’s initial suspicions of hyperlexia and concerns regarding her son’s lack of social behaviors had been temporarily allayed by the chair of the child development institute who had instead attributed it to his being a genius. Sharon’s son, Carl, on the other hand, did not receive the autism diagnosis till the late age of 12 likely because they were then living in a developing country with little access and knowledge of symptoms related to autism, or because the professionals testing him at earlier ages had limited understanding of autism. In any case, Carl’s having “missed the boat” for early intervention services was a sharp reminder of the need for early intervention, as echoed by parents’ in Sperry et al.’s study.
(1999), and for increased autism awareness in professionals. Had these two families received the diagnosis earlier, they might have been able to provide more appropriate interventions for their sons at an earlier age, when the interventions would have been more effective.

Reaction to diagnosis. Although some children had severe symptoms and complications from birth and their diagnosis was not a surprise, it was no less distressing for parents. DeMarle and le Roux (2001) noted that parents of children with disabilities went through a grieving process for the loss of parents’ initial expectations and dreams for their child, regardless of the severity of the disability. In this study, this principle applied also to parents who already knew their child had a disability even prior to receiving the diagnosis. However, the diagnosis was also a relief for parents who had been struggling with the child’s behaviors without understanding the underlying cause, as it gave them a label which made supports available to them. The period of uncertainty where parents knew something was wrong but not what it was, and therefore how to address the issue and help their child has been noted as a stressor for parents in the pre-diagnosis stage (Rolland, 2005). This was especially evident for Grace who had not initially understood Nick’s behaviors and found it stressful not knowing when and what would trigger a meltdown. Receiving the diagnosis had provided her with services and supports to help Nick. Hence, although receiving the diagnosis was often a stressor, it provided the key to accessing supports parents needed, and gave them an understanding of their child's behaviors. Key supports needed at this point were informational and instrumental supports (Dunst et al., 1986), which are discussed next.

Informational and instrumental supports. Informational supports at this stage were especially useful because parents were often unfamiliar with autism and the early intervention system. Informational supports in this study included helping parents understand what autism is and the implications of having a child with autism, as well as providing parents with information about services and supports available. Similar findings were
reported in a survey of parents of children with ASD (Moh & Magiati, 2012) who found the information provided by professionals immediately after the diagnosis most helpful as it helped them understand the diagnosis and provided information on available interventions for their children. In a similar vein, instrumental supports at this stage, in the form of practical help from service providers, family, and friends, were particularly helpful as they addressed parents’ need for services for their child. For instance, the presence of home and community assistants provided parents with an additional person to support the child, allowing them some downtime from caregiving responsibilities as well as time to address other issues such as running household errands, or caring for their other children. Parents also had to be equipped with tools and strategies in dealing with challenging or difficult behaviors, which was often taught through parent education and training workshops, as well as suggestions from service providers.

**Early to Middle Childhood (Approximately Ages 8 to 13)**

Key themes extending from the early childhood to the middle childhood stage include balancing work and family needs, dealing with persisting difficult behaviors or emergence of new challenging behaviors, school-related issues, efficacy of therapies and the importance of financial supports.

**Balancing family and other demands.** The families at the early and middle childhood stage tended to be young (parent ages ranged from 33 to 43) and very likely are adjusting to their child’s school and therapy schedules, while establishing themselves in their jobs, explaining the need to balance work and family life. For instance, Joan and John were in graduate programs when Leroy was younger. Hence the logistics of taking their child to and from appointments was not easy as parents’ schedules were not always flexible. This issue was raised in Matthews, Booth, Taylor, and Martin’s (2011) study on work-family challenges which found that workplace flexibility was a significant issue. Similarly, parents discussed
the need to re-arrange their work schedules, as well as career trajectories, to meet the demands of caring for the child with ASD and their family. This is reflective of tasks associated with the “families with young children” life cycle stage (Carter & McGoldrick, 2005), where parents work together to raise the child and manage finances and household tasks. In these families, however, the child-rearing task is complicated by the therapies and related expenses associated with having a child with autism.

Parents in this study also spoke of the need to spread their resources, care, and attention for their other children. This finding was similar to Woodgate et al.’s (2008) study where parents had stressed the need to maintain a healthy balance between parenting the child with autism and meeting the needs of their other children and themselves. Parents in Woodgate et al.’s (2008) study also found themselves missing a ‘normal’ way of life as a result of caring for their child with autism. Similarly, parents in this study had made sacrifices such as not focusing on career advancement (Sarah), foregoing wants such as going out on dates or getting a new clothes (Mary), or staying married at the expense of their own happiness (Sadie). However they viewed these as “tradeoffs” that provided their child with supports and interventions, leading to improvements in their child’s symptoms and developmental progress.

**Challenging behaviors.** Challenging behaviors were stressors noted by several parents from early to middle childhood occasionally lasting into adolescence. The presence and persistence or even emergence of new challenging behaviors in the children described in this study supports Bekhet et al.’s (2012) review of the relationship between challenging behaviors and severity of symptoms and parental stress and psychological distress. Challenging behaviors such as tantrums, irregular sleep patterns, wandering tendencies, and lack of safety awareness were distressing as parents were constantly vigilant for anything that would trigger a meltdown, and anticipating and pre-empting potential danger concerns. In
other cases, the nature of the behaviors changed (e.g., Leroy’s meltdowns turned into perseverating over incidents), which meant parents learned to adjust their methods of comforting and redirecting. Through interventions and possibly with the maturing of the child however, the behaviors were sometimes resolved which was a relief for parents. The school and service providers often provided much support in addressing challenging behaviors and improving the child’s language and functional skills. Hence school- and service-related issues, discussed next, were often critical factors contributing to parents’ experience of stress or support.

**Teacher experience and understanding.** As the success of the child in school appeared dependent on how adept the teacher was at supporting their child, parents were particularly concerned with school-related factors such as teachers who understood autism and were able to appropriately handle their child. Negative incidents such as inappropriate handling of the child, abuse, and refusal to consider parental input, aggravated the child’s behaviors, and were extremely stressful events for parents like Sadie and Rose. This was consistent with Starr and Foy’s (2012) observations that parent satisfaction with their child’s education depended on the school’s ability to manage the child’s behavior, teacher’s understanding of autism, and teachers’ collaboration and communication with parents. Similar issues were reported by parents in White et al.’s (2012) study who were asked to describe their experiences of crisis. Given that school-related stressors appeared to be significant stressors for several parents during their child’s school-age years in this study, it indicates a need to examine the possible interactions between school-related factors (e.g., teacher experience with and knowledge of autism, school’s willingness to work with parents) and parental stress.

In addition, school-related themes appeared to be child-focused and parent-related. Child-focused themes included teachers’ knowledge of autism and ability to work effectively
with the child, while parent-related themes included teacher-parent communication and the school’s willingness to consider parental input. These themes were considered supportive when the school and teachers were willing and able to help their child. However, they were considered stressors when the school and teachers were unable to or refused to collaborate with parents in supporting the child. This was the case for Rose and Sadie, which led to negative consequences for all parties involved (i.e., the child, school, and family). For instance, Sadie launched a successful lawsuit when her son’s school refused to provide adaptive P.E. However, the lawsuit took tremendous time and effort to prepare for, and in the meantime, her son had to do without modifications in P.E. class. This has implications for practice in terms of educating school personnel about autism, training them to collaborate with parents as partners in supporting the child, and taking into consideration parents’ opinions and needs.

**Intervention efficacy.** The efficacy of intervention in terms of improved behaviors and skills was often a support mentioned from the early to middle childhood stages. Parents were relieved when challenging behaviors were reduced and thrilled when they observed behavioral improvements and progress in their child’s skills. Several parents in this study talked about celebrating every step of progress even though these would be minor events in a typically developing child. As Mary mentioned, because they got to see the child’s progress in “slow motion” and progress had been so hard-won, every progress made was a cause for celebration. Similarly, parents in Woodgate et al.’s (2008) study, which described the lived experiences of children with autism, noted the importance of cherishing milestones even if they occurred differently from those of typically developing peers. In both studies, achieving these milestones gave parents a sense of hope for their child’s development and future progress.
Financial supports. Financial supports were critical for parents as they provided access to early intervention services, such as behavioral therapy, that were essential but too costly. Even for parents with higher income, finances were a concern because of the high costs of therapies and the need to provide for their other family members. Several parents mentioned having to forego services because the high cost of therapy together with the limited insurance coverage or financial waiver support made therapies inaccessible. This echoed the reflections of both parents and service providers in the focus groups organized by the National Early Childhood Technical Assistance System (NECTAS) (Sperry et al., 1999). The fact that these issues were still prevalent despite concerns being raised to the Office of Special Education Programs (OSEP) over a decade ago suggests the difficulty in addressing the increasing financial needs in the face of limited financial resources (Sperry et al., 1999). As Guralnick (2005) noted in his discussion of barriers to optimal family interaction patterns, financial needs are of great concern for parents due to the considerable out-of-pocket expenses incurred despite insurance coverage and other sources of financial aid. The financial issues highlighted by parents in this study suggest the need for greater insurance coverage and for policy stakeholders at the school and state level to consider the needs and capacities of the family as well as those of the child. Interestingly, financial issues were highlighted by parents particularly with reference to the early childhood and middle childhood stages. This is possibly because by the high school years and after, parents may have already been receiving some form of financial supports, had more established incomes, or already prepared future financial support for their child after their deaths. For instance, Joan and John are now university professors compared to when Leroy was younger and they were both graduate students; Sadie and her husband have set up a trust fund for their son when they pass away.

The most salient themes shared across the early and middle childhood years were focused primarily on issues related to the school and service providers, as well as financial
concerns and the need to balance work and family commitments. However, as the child approached adolescence, parents became more concerned about what happens after the child leaves the school system, which will be discussed in the next section.

**Adolescence (Approximately Ages 14 to 19)**

At the adolescence stage, the family is in the “long haul” phase that families of individuals with a chronic disability go through (Rolland, 2005), and families have to continually prepare for and adapt to the transitions accompanying the individual with autism. In this case, transition from the school system and school-based services is a major phase of the adolescent’s life. Hence, key issues in adolescence were primarily related to concerns regarding the adolescents’ level of independence and ability to transition from high school, and the adolescent’s limited social skills, which had implications for the adolescent’s future working life.

**Transition from high school and independence.** The transition from high school was a major event parents were concerned about at the adolescent stage. As McGoldrick and Carter (1992) noted, families with adolescents typically establish permeable boundaries allowing adolescents increased independence and to move in and out of the family system. In families of individuals with autism however, parents may still have the same goals but the adolescent with autism may not have achieved a sufficient level of independence to move out of the family system. Hence independence was a key theme emphasized in adolescence as parents prepared their adolescent to exit the school system and to enter adulthood. This aligned with the “families with adolescents” stage in the family life cycle theory (Carter & McGoldrick, 2005) as the parents in this study were very focused on helping their child achieve as much independence as they could at the adolescence stage. The two families in the adolescent category of this study had hopes that their sons would eventually live independently, and find jobs they enjoy to support themselves. Although both families
acknowledged limitations in their sons’ present social-emotional skills and functional skills (e.g., time and financial management), important for independent living and maintaining employment, they hoped their sons would eventually learn these skills, enjoy their work, and, if possible, live independently in future. Similar to the needs they had when entering the early intervention system in early childhood, parents needed information about adult services as well as programs assisting in the transition process to a new phase of the soon-to-be young adult’s life. The transition concerns at this stage suggest a need for agencies providing adult supports to collaborate with schools to facilitate the transition planning and implementation.

**Social skills issues.** Adolescence also appeared to be a stage where social skills became a primary concern in this study. One of the adjustments families make at the “families with adolescents” stage (McGoldrick & Carter, 1992) is expanding the family system to accommodate friends that adolescents may bring in. However, many adolescents with autism have few or no friends (Seltzer et al., 2004) due to impairments in their social skills, which was a concern voiced by some of the parents in this study. When the child was younger, parents could provide social groups through activities and play groups. However, by adolescence, social groups are usually formed by youth themselves. Hence an adolescent with autism who lacks the social skills needed to develop and sustain friendships may find himself lacking a peer social group. This supports findings from a systematic review of 24 studies on school-age friendships by Petrina, Carter, and Sephenson (2014) which indicated that adolescents with ASD compared to younger children with ASD reported lower levels of friendship quality possibly due to impairments in social communication and a difference in their perception of the role of friendships. As Sharon and John explained, their adolescents may have a desire to participate in normative events (e.g., having a girlfriend, learning to drive a car) but may not have sufficient social skills or may require more assistance to help them achieve those goals. Hence parents indicated the need for courses or social groups to
facilitate social interaction for their adolescent. The importance of social skills development also explained Sharon’s dismay at the high school’s lack of social skills courses. This highlights the need for schools to provide social skills training and opportunities for adolescents to interact with peers in a safe environment, especially since the school is a place where adolescents spend a large portion of their time with same-age peers.

While concerns at adolescence were related to the preparation for the transition from high school, key concerns at adulthood, discussed next, were related to sustaining supports for the young adult. These included the search for adult supports and preparations for the adult after the parents’ deaths.

**Adulthood (Approximately Ages 20 and Above)**

Adulthood was accompanied by the limited availability of adult supports and the parents’ preparations for the future. As Fulmer (2005) noted in his review on the transition to adulthood within the context of the family, one of the developmental tasks of typically developing young adults is preparing to enter the workforce while the family’s role is to provide practical and emotional support during this period. For young adults with autism however, this period of time may be prolonged indefinitely as the young adult may enter an assisted form of employment and thus not be fully independent of the family. Hence, parents were especially concerned about sustaining needed supports for their young adult.

**Need for adult supports.** The limited amount of supports for adults with autism, specifically moderate to severe autism, was a stressor at the adolescent and adulthood stage. This was emphasized by Sadie, who was still the primary caregiver for her child, even by the early adulthood stage. As she highlighted, even when school-based services have ceased, the young adult with autism still requires support which the parent now needs to search – “the need doesn’t stop”. This is a concern in light of the benefits of supported employment (Garcia-Villamisar & Hughes, 2007) and the value of supports such as the VRS. The need for
adult supports is consistent with Smith, Greenberg, and Mailick’s (2012) review examining outcomes of adolescents and adults with ASD and their family’s role in the transition to adulthood, which noted that the loss of services and lack of daytime services were common issues in adolescent and adult outcomes. Parents in Gray’s (2002) longitudinal study also reported similar concerns such as limited adult services and poor quality of services that were available. In this study, Sadie’s frustration was compounded by the realization that the few services and programs available catered mainly to individuals on the extreme ends of severity levels – those with higher-functioning forms of autism, or those with severe and/or multiple disabilities.

Preparations and expectations for future. Preparation for the future was a key feature of adulthood in this study. In typical families, the life cycle stage of “launching children and moving on” (Carter & McGoldrick, 2005) is accompanied by exits and entries, such as the moving out of the home for the young adult and acquiring of in-laws and grandchildren. However, in families of individuals with ASD, this process is likely to be delayed or absent. In this study the two families in the adulthood stage had preparations for the future when the parents were no longer around, with the expectation that their young adult would require some form of assistance for the rest of his life. They were in fact willing and prepared to have their sons stay with them for the rest of their lives. This supports findings from the review on developmental trajectories of adolescents and adults with autism by Seltzer et al. (2004) that most adults with autism, regardless of severity level, remained dependent on their families and were likely to live with them or in residential homes. However, a few parents like Sharon, Joan, and John, whose sons were verbal and could perform daily tasks albeit with constant reminders and guidance, still retained hopes that their child would be able to live somewhat independently in the future. Some parents in the earlier
stages, such as Mary, Rose, Eric, appeared to share similar expectations, probably because of the severe limitations of their child’s functional, language, and social skills.

**General Themes**

Apart from stressors and supports specific to particular stages, some themes were not stage-specific or were shared across stages. Factors that were not stage-specific included stressors related to parent’s jobs and societal lack of understanding of autism. Themes shared across stages included concerns for the future, the importance of informal supports from family and friends, and parent internal strengths.

Factors that were not associated with specific stages but contributed to parental stress and support were external factors such as stress related to parent’s jobs, (e.g., bad work environment) and societal lack of understanding of autism. The latter was stressful for parents when they observed that their child was not accepted by peers or the people around them. In addition, as the child grows older, he may be more conscious of his differences from his peers, which may be distressing for him and the family, as was the case for both families in the adolescence category. Also, the sometimes ‘invisible’ nature of autism (Patterson & Blum, 1996) led to misunderstanding of the child and parent as was the case for Grace when Nick was young.

**Concern about the future.** Concern about the child’s future was mentioned by all parents, with the exception of Grace. Several parents had mentioned not knowing how far their child could progress which, as Smith, Greenberg, and Mailick (2012) noted preventing them from developing clear expectations of the child’s future. This, in turn, was a constant stressor for all parents, especially regarding the time when the parents have passed away (Patterson & Blum, 1996). Grace, on the other hand, had an older son, James, who had agreed to be Nick’s guardian. This appeared to have alleviated her concerns for Nick’s future and she did not articulate further concerns about Nick’s future apart from what would happen
when Nick’s three current service providers left their jobs. Similar to White et al.’s (2012) findings, Joan, Sharon, and Sadie were understandably concerned during the adolescent period about the time when their child ages-out of school-based services and what supports are available for their sons after exiting the school system.

**Parent support and education groups.** Interestingly, parent support groups were not always a source of support for parents. The few parents involved in parent support groups were in the early childhood stage (e.g., Sarah and Mary) who had formed strong friendships through these support groups and were very appreciative of the support groups. However, several parents such as Eric, Joan, John, and Sadie were not able to join due to a lack of time or did not find them useful (e.g., about higher functioning autism). On the other hand, parent education courses were mentioned as important supports as parents appreciated the practical advice and tools provided. This supports Papageorgiou and Kalyva’s (2010) finding that parents’ primary motives for participating in support groups were, in order of importance, to be kept abreast of recent developments in the autism field, and to receive practical support and advice, followed by socializing with other parents and receiving psychological support.

**Informal supports.** Informal supports from family members and friends or parents of children with autism were also mentioned across stages. At the early childhood stage, supports from family and friends often came in the form of practical help such as babysitting and financial assistance, or emotional support such as lending a listening ear to parents’ concerns and frustrations, and accepting and understanding the child. Parents of children with autism, or other disabilities, were cited as major sources of support as they were able to empathize and offer comfort or advice. This was especially in light of the loss of friendships experienced by some parents when their child’s disability became apparent. Similar to the parents in Woodgate et al.’s (2008) study who reported their experience as “living in a world of our own”, some parents in this study also reported a sense of social isolation. Therefore,
informal social supports may serve as a buffer to this sense of isolation, as the same parents who had reported a sense of isolation resulting from the autism-related symptoms, Mary and Sarah, were also the ones who had emphasized the importance of the supports from other parents of children with autism.

Interestingly, although the literature suggests that informal supports from family and friends are critical supports at the adolescence and adulthood stages, when formal supports are reduced, this was not highlighted in this study. All parents acknowledged extended family members or parents of children with disabilities. However, parents in the adolescence and adulthood stages did not appear to place much emphasis on them. It is possible that parents were more focused on talking about their formal supports (e.g., school, service providers) during the interview. In fact, Mary and Sarah, parents in the early childhood stages, were the ones who were very enthusiastic when talking about supports from parents of children with autism. It is possible that the ability to bond and connect with people who were going through the same experiences had a greater impact on them than on parents who had been dealing with the diagnosis for a longer period of time.

**Siblings.** In families with multiple children, the siblings of the child with autism were an important source of support for parents across the stages. As Greef and van der Walt (2010) noted in their study examining factors of resilience in families of children with autism, having capable siblings who helped in the caregiving responsibilities was a great help for parents. In this study, the child with autism was usually more responsive to his/her sibling than to other same-age peers (e.g., Mark, Alice). Hence, siblings, even at a young age, were supports for parents in providing the focal child with a playmate that he/she would interact with socially. In addition, siblings also provided parents with a form of assurance that the child with autism would have some form of support in the future when they were no longer around (e.g., Eric, Grace).
**Parent strengths.** A critical source of support evident from the interviews was the parents’ internal strengths. Parents displayed tremendous resilience and strengths in the face of challenges in achieving supports and caring for their child. The fighting spirit evident in all parents, whether or not it was articulated explicitly, demonstrated their love for their children and their persistence. Walsh (2003) defined family resilience as the product of the family’s growth and development in the face of adversity. This growth was evident in the parents in this study. Upon self-reflection, parents were sometimes surprised by their own ability to fight for their child and the amount of work they had put into helping their child. As in Bayat’s (2007) study identifying factors of family resilience, parents also demonstrated a positive outlook and appreciation for their child and experiences. Key qualities all parents demonstrated were their fighting spirit in getting all the supports they could for their child and in persevering to do all they could for their child. These qualities were crucial internal supports for parents.

In examining the stressors and supports parents of individuals with moderate to severe autism experience across the ages, it was evident that parents experienced stressors unique to specific stages such as diagnosis-related issues at early childhood and transition preparation concerns at adolescence. However, some stressors, such as parental worry for child’s future, were shared across stages. Similarly, the nature of supports were also related to the stages in that instrumental help from formal and informal sources were critical especially during early and middle childhood, while informational support was critical at transitions, such as the entry into early intervention and the transition out of the school system. Nonetheless, informal supports such as family members or friends were also consistent sources of support across the ages. Of vital importance across stages was the tremendous resilience and internal strengths parents possessed helping them to overcome those stressors. The following
sections will discuss the limitations of this study and highlight the implications of this study for future research directions and practice.

**Limitations of This Study**

Despite the importance of this study for educators and service providers, this study had some limitations. A limitation of this study is its small sample size. Due to time and resource constraints, this study was not able to recruit more participants which may have provided a more representative sample. Hence this study offers a small glimpse into the experiences of parents of individuals with moderate-severe autism. Future studies could recruit additional participants with more varied backgrounds to achieve a fuller understanding of parenting experiences.

Another limitation is that participants were self-selected. Hence it is not known if there would be differences in experiences between those who chose to participate in this study and those who did not, and if there were any underlying reasons for those differences. Also, data from this study were obtained through a single interview with parents which may not have been enough to elicit and elaborate on other topics. Hence information which could have been obtained through multiple interviews was not available.

In addition, this study was cross-sectional in design; hence no longitudinal data was collected. Instead, retrospective self-reported data was collected from parents regarding their experiences prior to the time of interview. For instance, parents of adults were asked to recall their experiences of stress and supports from their child’s early childhood to the present moment and how these have changed over time. Future studies may consider a longitudinal design, following the same individuals from early childhood to adulthood, which may provide more accurate data.

**Directions for Future Research**

As this study examined only the perspectives of parents of individuals with moderate
to severe autism, it may be helpful to examine those of schools and service providers in order to fully comprehend the limitations and supports available at each stage. Future research may also consider examining a larger sample of parents including parents of individuals with higher functioning autism whose parenting experiences may be strikingly different, or surprisingly similar.

In addition, the children of parents in the adulthood group were in their early twenties. Hence issues tend to center around their finding and maintaining a job, and thinking about the future. However, the supports and concerns that parents of older adults with ASD may be different, which were not examined in this study. As adulthood encompasses a larger age range than early childhood, middle childhood, and adolescent ages combined, there is a need for future studies to explore this stage of life in order to better understand the needs of families with older adults with autism.

Lastly, future research may consider using the double ABCX model of adjustment and adaptation by McCubbin and Patterson (1983) as a theoretical framework for examining parental stressors and supports over time. The Double ABCX model includes post-crisis variables such as the additional culmination of stressors over time, new and existing resources, as well as changes in the meaning families give to their situation. The inclusion of a parent perception component, which can affect parent adaptation, would provide a better understanding of how parents cope with the stressors they encounter. Hence, longitudinal studies examining parental stressors and supports could take into consideration the impact of the accumulation of stressors, the presence of existing and new supports, as well as the family’s perception of their situation at various points in time.

Implications for Practice

Several implications for practice can be drawn upon examination of the factors that parents found stressful or supportive. These relate to implications for schools and teachers,
provision of financial assistance, and access to services at particular stages.

**Teachers and service providers.** The extremely negative experiences some parents had with schools point to a need for greater awareness and understanding of children with autism and education for teachers in appropriate practices in handling and teaching the child. In addition, there appears to be a need for accountability especially in cases where inadequate supports were provided or when cases of mistreatment occurred. It is important that teachers and school staff are educated in understanding how to meet the needs of children with autism appropriately. This is especially so given the rising number of children diagnosed with autism (Blumberg et al., 2013) who will enter the classroom in future years.

**Family-centered service provision.** The informational supports needed for families at the point of diagnosis and entry into the early intervention system, as well as at the transition to adulthood were key themes at major points of transition. Families in this study appreciated having support not only in terms of therapy hours for the child, but also respite and home or community assistance, pointing to the need for a more family-centered system of early intervention beyond the birth-3 years, specifically focusing on the late adolescent and adulthood stages.

**Finance and systemic issues.** Despite the financial supports from Medicaid, insurance, and other public waivers, finances were a key stressor for parents. Services in the schools were at times not provided due to budget restrictions. Yet, findings from Odom, Parrish, and Hikido’s (2001) cost-benefit analysis comparing the costs of inclusive and traditional special education preschool services suggest that inclusive models were less costly than traditional models. This indicates the benefits of providing services to accommodate the child in an integrated setting at this early childhood stage, especially when early intervention is more beneficial for the child than at later stage when resources may tend be more directed at maintaining the individual’s skills. In a field facing increasing financial needs and limited
resources, it is critical that the long-term implications of providing intervention services are considered. In addition, given the high level of mobility of families among states in the U.S., having a nationwide system where financial assistance waivers are concerned, as suggested by Rose, may be helpful for parents to navigate the financial assistance and early intervention systems when they relocate to a new state.

This study explored the experiences of parents in terms of the supports and stressors at each stage of the child’s life cycle. As parents are a crucial source of support for children with autism, it is essential that their needs are understood and met. The findings from this study highlight what has been helpful for them as well as the areas of need contributing to their parenting abilities and experiences. This is of importance for several stakeholders including educators, service providers, as well as policy makers as they take into consideration how to support the family, hence supporting the child. At the school and service level, the interactions parents have with schools and service providers directly impact their experiences and contribute to their sense of support or stress. However, systemic issues such as the financial assistance and policies for service provision indirectly contribute to the interaction between schools, services, and parenting experiences. The nature of these supports and stressors vary across the age level and hence, there is a need to consider the life cycle stage of the child and accompanying family needs when planning and implementing supports and services for the child with autism. As several parents noted at the end of the interviews, they see the importance of this study and want their voices to be heard. The quality of life for child and family are intricately linked; the outcomes of providing supports for child and supports for the family are intrinsically related. Hence it is vital that educators, service providers and other stakeholders keep the needs of the family in mind as they work to serve the child.
APPENDIX A: RECRUITMENT FORMS

Recruitment Email

Dear Parent,

I am a master’s student in the Early Childhood, Special Education, and Literacy program at the University of North Carolina at Chapel Hill. I am currently conducting my thesis research on parental stress and supports in parents of individuals with moderate to severe autism or autism spectrum disorders (ASD). The purpose of my study is to understand the challenges and supports that parents face across the life cycle stages of the child. As such, I hope to interview parents of individuals who have moderate to severe ASD. My hope is that this study will help professionals better understand parents’ experiences and needs, and ultimately improve their services to families of individuals with ASD.

This invitation is open to parents of individuals with moderate to severe ASD. You may be eligible if you have a child/youth/adult with moderate to severe ASD.

How you will be involved:

❖ Interested parents will be asked to complete a 15-20 minute screening questionnaire about your child’s autism symptoms. This helps the study confirm that your child has moderate to severe ASD.

❖ Once this has been completed and you meet the eligibility criteria, you will be invited for an interview at a mutually convenient time and location. The interview will take approximately 1 to 1.5 hours.

❖ During the interview, you will be asked to complete a demographic information sheet and asked about your experiences of parenting an individual with moderate to severe autism. These include the challenges and supports you have encountered. You are also welcome to bring any pictures or documents that you think might help me better understand your experiences.

If you would like to participate in this study, or have any questions, please feel free to contact me at 919-619-7537, or at xueyany@live.unc.edu.

If you know of parents who may be interested to participate, I would appreciate it very much if you could forward this email to them.

Thank you for your time!

Sincerely,
Xueyan Yang
School of Education
University of North Carolina at Chapel Hill
Participants needed for research study

Study on Supports and Stressors in Parents of Individuals with Autism

This is an invitation to parents to participate in a study on supports and stress in parents of persons with moderate to severe autism. This study hopes to help professionals better understand parents’ experiences and needs, and ultimately improve their services to families of individuals with ASD.

You’re eligible if:
✓ You are a parent of a child/youth/adult with moderate to severe autism/ASD

What will you be doing?
✓ Complete a 15-20 minute questionnaire about your child to determine if you are eligible for this study
✓ Complete a demographic information sheet
✓ Be interviewed about your parenting experiences, the challenges and supports you face. This interview takes about 1-1.5 hours

If you would like to participate in this study, or have any questions, please contact me at 919-619-7537, or at xueyany@live.unc.edu.

If you know of parents who may be interested to participate, please feel free to pass on information about this study to them.

Thank you!
Xueyan Yang
School of Education
University of North Carolina at Chapel Hill
APPENDIX B: CONSENT FORM

University of North Carolina at Chapel Hill
Consent to Participate in a Research Study
Adult Participants

Consent Form Version Date: 12/11/13
IRB Study # 13-3808
Title of Study: Parental Perspectives of Stress and Supports Across the Life Cycle of Individuals with Moderate to Severe Autism
Principal Investigator: Xueyan Yang
Principal Investigator Department: School of Education
Principal Investigator Phone number: 919-619-7537
Principal Investigator Email Address: xueyany@live.unc.edu
Faculty Advisor: Dr. Harriet Able
Faculty Advisor Contact Information: hable@email.unc.edu

What are some general things you should know about research studies?
You are being asked to take part in a research study. To join the study is voluntary.
You may refuse to join, or you may withdraw your consent to be in the study, for any reason, without penalty.

Research studies are designed to obtain new knowledge. This new information may help people in the future. You may not receive any direct benefit from being in the research study. There also may be risks to being in research studies.

Details about this study are discussed below. It is important that you understand this information so that you can make an informed choice about being in this research study.

You will be given a copy of this consent form. You should ask the researchers named above, or staff members who may assist them, any questions you have about this study at any time.

What is the purpose of this study?
The purpose of this study is to understand the challenges and supports parents of individuals with moderate to severe autism spectrum disorders (ASD) encounter across different stages of the child’s life cycle.

You are being asked to be in the study because you are a parent of a child/youth/adult with moderate to severe autism.

Are there any reasons you should not be in this study?
You should not be in this study if you are not a parent of a child/youth/adult with moderate to severe autism.

How many people will take part in this study?
There will be approximately 6-8 participants in this research study.

How long will your part in this study last?
The interview will take approximately 1-1.5 hours.

What will happen if you take part in the study?
You will be invited to participate in a one-to-one interview and to bring any documents or artifacts that you think might help me understand your experiences better. I will ask your permission to record the interview and to make a copy of any documents or artifacts that you bring to the interview.

After the interview has been transcribed, I will send a copy of the transcript and a summary of the main topics we discussed for you to verify the content.

What are the possible benefits from being in this study?
Research is designed to benefit society by gaining new knowledge. You will not benefit personally from being
in this research study.

What are the possible risks or discomforts involved from being in this study?
The risk for your involvement in the study is minimal. Still, the topics may conjure up sensitive emotions. Questions have been designed to respect potential areas of sensitivity. In addition, I will take measures to protect your identity such as, removing your name from all interview transcripts and notes. I will create a pseudonym for you and for all identifying information such as locations and other names. You may withdraw from participation in the study at any point.

What if we learn about new findings or information during the study?
You will be given any new information gained during the course of the study that might affect your willingness to continue your participation.

How will information about you be protected?
After the interviews are transcribed, your name and the names of your children, schools, or locations mentioned during the interview will be changed to pseudonyms prior to data analysis. Thus, any personally identifiable information will be removed from the interview transcripts. Only the primary investigator, myself, will have access to the identifiable information.

Participants will not be identified in any report or publication about this study. Although every effort will be made to keep research records private, there may be times when federal or state law requires the disclosure of such records, including personal information. This is very unlikely, but if disclosure is ever required, UNC-Chapel Hill will take steps allowable by law to protect the privacy of personal information. In some cases, your information in this research study could be reviewed by representatives of the University, research sponsors, or government agencies (for example, the FDA) for purposes such as quality control or safety.

Audio recordings and other information containing identifiable linkages will be destroyed after the study has been completed.

Please check the line that best matches your choice:

Permission for audio recording:

_____ OK to record me during the study
_____ Not OK to record me during the study

A copy or photograph of the documents/artifacts that you bring will be taken in order to supplement the themes and topics that are raised in the interview.

Permission for copy of documents/artifacts to be made:

_____ OK for a copy of the documents/artifacts I bring to be made
_____ Not OK for a copy of the documents/artifacts I bring to be made

What if you want to stop before your part in the study is complete?
You can withdraw from this study at any time, without penalty. The investigators also have the right to stop your participation at any time. This could be because you have had an unexpected reaction, or have failed to follow instructions, or because the entire study has been stopped.

Will you receive anything for being in this study?
You will receive a $20 gift card from a local grocery store upon completing the entire interview. Participants who withdraw or have to leave early after completing at least 45 minutes of the interview will be given a $10 gift card.

Will it cost you anything to be in this study?
It will not cost you anything to be in this study.

What if you have questions about this study?
You have the right to ask, and have answered, any questions you may have about this research. If you have
questions about the study (including payments), complaints, concerns, or if a research-related injury occurs, you should contact the researchers listed on the first page of this form.

**What if you have questions about your rights as a research participant?**
All research on human volunteers is reviewed by a committee that works to protect your rights and welfare. If you have questions or concerns about your rights as a research subject, or if you would like to obtain information or offer input, you may contact the Institutional Review Board at 919-966-3113 or by email to IRB_subjects@unc.edu.

**Participant’s Agreement:**

I have read the information provided above. I have asked all the questions I have at this time. I voluntarily agree to participate in this research study.

________________________
Signature of Research Participant
Date

________________________
Printed Name of Research Participant

________________________
Signature of Research Team Member Obtaining Consent
Date

________________________
Printed Name of Research Team Member Obtaining Consent
APPENDIX C: LIST OF HELPFUL RESOURCES

List of Helpful Resources

These are a list of resources that I hope you will find useful. They contain information, updates, and resources relevant to families of individuals with autism.

**Autism Action Partnership**
http://www.autismaction.org
Contains information resources for families of individuals with autism on various topics and services.

**Autism Speaks**
http://www.autismspeaks.org
http://www.autismspeaks.org/autism-apps
They have a page that specifies apps according to different filters (age, function, device)!

**Autism Society**
http://www.autism-society.org
Contains research and news for parents of individuals with ASD, the individuals themselves, and professionals.

**Autism Support Network**
http://www.autismsupportnetwork.com
Community of parents and individuals with ASD.
Under Resources, you can specify your country and state, and it provides a list of places that provide support/therapy for autism.

**Autism Today**
http://www.autismtoday.com
Contains information for resources and recreation, and personal stories of families of individuals with autism, researchers, doctors, teachers and so on.

**Cindy's Autistic Support**
http://www.cindysautisticsupport.com/parents.html
This is a teacher's collection of resources geared more toward younger, school-aged children. The link brings you to resources that parents may find useful.

**Interactive Autism Network Community**
http://www.iancommunity.org/cs/home
This website contains research, discussions, news on different topics in autism.
### APPENDIX D: DEMOGRAPHIC FORM

#### Demographic information

**About You**

| Your relationship to child: | ☐ Father  
<table>
<thead>
<tr>
<th></th>
<th>☐ Mother</th>
</tr>
</thead>
<tbody>
<tr>
<td>Age:</td>
<td></td>
</tr>
</tbody>
</table>
| Ethnicity:                  | ☐ Caucasian  
|                             | ☐ Hispanic  
|                             | ☐ African American  
|                             | ☐ Asian  
|                             | ☐ Other: __________________________ |
| Marital status:             | ☐ Single  
|                             | ☐ Married  
|                             | ☐ Separated  
|                             | ☐ Divorced  
|                             | ☐ Widowed |
| Highest Educational Level Completed: | ☐ Less than high school  
|                             | ☐ High school/GED  
|                             | ☐ 2 year college (Associate)  
|                             | ☐ 4 year college (BA, BS)  
|                             | ☐ Masters degree  
|                             | ☐ Doctoral degree  
|                             | ☐ Professional degree (MD, JD) |
| Health status               | ☐ Good  
|                             | ☐ Fair  
|                             | ☐ Poor |
| Occupation:                 |         |
| Household income range:     | ☐ < $50,000  
|                             | ☐ $50,000-$69,999  
|                             | ☐ $70,000-$89,999  
|                             | ☐ $90,000-$124,999  
|                             | ☐ > $125,000 |

**About Your Family**

<table>
<thead>
<tr>
<th>Number of children</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Age and gender of children</td>
<td></td>
</tr>
<tr>
<td>Number of children with disability</td>
<td></td>
</tr>
<tr>
<td>Number of other family members with disability</td>
<td></td>
</tr>
</tbody>
</table>
### About Your Child/Youth with Autism

<table>
<thead>
<tr>
<th>Child’s Age</th>
<th></th>
</tr>
</thead>
</table>
| Gender      | ☐ Female  
☐ Male |
| Type of diagnosis | ☐ Autistic Disorder  
☐ Asperger Syndrome  
☐ PDD-NOS  
☐ Other: |
| Age of diagnosis |  |
| Severity of autistic symptoms | ☐ Moderate  
☐ Severe |
| Presence of other special needs/disabilities | ☐ None  
☐ If yes, please describe briefly: |
| Current educational level | ☐ Toddler  
☐ Preschool  
☐ Kindergarten  
☐ Elementary  
☐ Middle school  
☐ High school  
☐ 2 year community college  
☐ 4 year college  
☐ Graduate student  
☐ Not currently studying |
### About Your Adult Child with Autism

<table>
<thead>
<tr>
<th>Child’s Age</th>
<th></th>
</tr>
</thead>
</table>

| Gender | □ Female  
 □ Male |
|---------|--------|

| Type of diagnosis | □ Autistic Disorder  
 □ Asperger Syndrome  
 □ PDD-NOS  
 □ Other: |
|-------------------|-------------------|

<table>
<thead>
<tr>
<th>Age of diagnosis</th>
<th></th>
</tr>
</thead>
</table>

| Severity of autistic symptoms | □ Moderate  
 □ Severe |
|--------------------------------|--------|

| Presence of other special needs/disabilities | □ None  
 □ If yes, please describe briefly: |
|-----------------------------------------------|--------|

| Highest Educational Level Completed: | □ Less than high school  
 □ High school/GED  
 □ 2 year college  
 □ 4 year college  
 □ Masters degree  
 □ Doctoral degree  
 □ Professional degree |
|---------------------------------------|--------|

<table>
<thead>
<tr>
<th>Current occupation:</th>
<th></th>
</tr>
</thead>
</table>

| Current living arrangements | □ Living with parents  
 □ Assistive living  
 □ Independent living |
|-----------------------------|---------------------|

| Marital status: | □ Single  
 □ Married  
 □ Separated  
 □ Divorced  
 □ Widowed |
|-----------------|--------|

| Annual income range: | □ < $50,000  
 □ $50,000-$69,999  
 □ $70,000-$89,999  
 □ $90,000-$124,999  
 □ > $125,000 |
|---------------------|--------|
APPENDIX E: INTERVIEW PROTOCOL

Description of the study
The purpose of this study is to better understand the stressors and supports parents of children with moderate to severe autism face across the life cycle of their child in order to help professionals better understand parents’ experiences and improve their services.

Please know that the information you provide in this interview will be confidential and no names will be used to identify you and your family in the analysis and in the final report. In addition, you have the option of opting out of this interview at any point in time. I will be audiotaping this interview and possibly writing notes as well so that it will help me keep a more accurate account of what we have discussed. I will also share with you a copy of the transcript and a summary of the points we discussed within 1-2 weeks of the interview so you can verify it.

Interview Questions

a) Please describe your child with autism.
   a. Does your child get along well with other children?
   b. How is your child doing in school/work/other setting?

b) What are some of your expectations, goals or dreams for your child with autism now at age ____? How have they changed over the years?

c) What are some of your concerns regarding your child with autism now at age ____?

d) How have these concerns changed from when your child was younger (time of diagnosis, middle childhood, adolescence)?

e) What are some of your child and family successes now?
   a. Examples: making all A’s, being in Scouts, holding a job…
   b. Please describe some of the positive experiences you have had as a result of caring for your child.

f) What are some sources of support or strength for you in dealing with your child with autism?
   a. Formal: school, teachers, therapists, etc.
   b. Informal: family members, extended family, friends, other parents of children with ASD, spiritual beliefs

g) What were some internal strengths you feel you, your child, or your family possessed that helped you in this journey?

h) What services and supports would be most helpful to you and your family from the time your child was first diagnosed to the present moment?

i) What advice would you give to parents who are just embarking on this same journey or going through the same thing as you?
j) Are there other issues you would like to share about the parenting successes and challenges relative to your child with autism?

We have reached the end of our interview. As mentioned earlier, I will send you a copy of the full transcription as well as a summary of the issues discussed for you to verify the information. Please feel free to edit it if you feel the points you raised were not accurately represented. And feel free to add information that you may think of after our interview. Thank you for your time!
APPENDIX F: SAMPLE FIELD NOTE

Child description
Sarah’s 5-year-old son, Mark, is verbal but has difficulties with functional language, sensory issues and tantrums. He is less reclusive now compared to previously, which appears to be the result of the ABA therapy he recently started. He now voluntarily joins his family, albeit engaging in parallel play, instead of staying alone in his own room.

Expectations, hopes, and dreams
Sarah and her husband had initially hoped Mark could be mainstreamed in kindergarten. Now they recognize that may not happen. They still hope he will have a “developmental burst” but have readjusted their expectations, and are doing the best they can for him.

Early years (prior to diagnosis)
As Sarah’s husband has relatives who have higher functioning autism, she was attentive for possible symptoms but did not realize Mark had autism as he was meeting his developmental milestones. Prior to diagnosis, the main stressor was his refusal to eat, which in hindsight was likely due to his sensory issues. Sarah only noticed Mark’s delayed development when he started preschool. She was also prompted to let Mark be evaluated, learning her to study about autism and recognizing the symptoms (e.g., stimming, lining up instead of playing with cars).

At diagnosis (3.5 years)
Sarah mentioned going through a mourning period upon receiving the diagnosis and the immense pressure to locate early intervention services. Supports at this time were the developmental pediatrician (who provided a list of resources and linked them with needed services), parent education classes (helped them understand autism and what to expect, and make friends), and neighbors who helped with babysitting and whose children provided social interaction for Mark.

However, 6 months after diagnosis, Mark’s behaviors became challenging. They also faced challenges such as dealing with Mark’s gastrointestinal issues, coordinating services, high cost of services, and balancing between work and family commitments. Fortunately, Sarah’s younger sister stayed with them for a year and helped care for Mark.

Now (at 5 years old)
Most of Mark’s challenging behaviors have been resolved. Finances are a stressor – Mark’s ABA therapy is more expensive than her husband’s medical school fees – but they have a relative who pays for Mark’s ABA therapy. She is also very appreciative of her friends, particularly of the other mothers of children with autism. However, she also notes feeling overwhelmed by the varied approaches therapists use and expect them to implement. They deal with it by choosing only what is needed.

Future concerns
Sarah’s concern for Mark is that he requires support but still needs integration with typically developing children. She is constantly worried about his future, but appears to be accepting that he may always require support from them.
APPENDIX G: SUMMARY OF INTERVIEW

Summary of Interview with Sarah, Son: Mark

Description of Child
- Mark is a 5-year-old boy who is verbal, but has issues with functional language.
- Character/Personality: Sweet, fun
- Interests: He likes cars
- He likes his older brother, Noel. He is less reclusive now compared to previously. Now he voluntarily joins and moves with the family instead of staying in his own room. The change seems to be due to the ABA therapy. He also has friends in his preschool class and neighborhood children that he likes.

Expectations, Goals, Dreams
- Initially: Parents were hoping he would be able to be mainstreamed in kindergarten
- Current: Recognize that he may not be able to, but are hoping he will have a developmental burst, and will hopefully have a typical adult life. But since it is uncertain what will happen, they have readjusted their expectations, accepted that this might not be the case, and are doing the best they can for him

<table>
<thead>
<tr>
<th>Supports</th>
<th>Challenges</th>
<th>Other Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>General</td>
<td>Concerns for future</td>
<td></td>
</tr>
<tr>
<td>Marriage</td>
<td>• Strong marriage</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Humor</td>
<td></td>
</tr>
<tr>
<td>Family members</td>
<td>• Husband’s sister who has a son with Asperger’s</td>
<td></td>
</tr>
<tr>
<td>Son</td>
<td>• Understanding of M.’s disability</td>
<td></td>
</tr>
<tr>
<td>Neighbors</td>
<td>• Swap babysitting</td>
<td></td>
</tr>
<tr>
<td></td>
<td>• Kids of similar age – allows M. to interact with kids his age.</td>
<td></td>
</tr>
<tr>
<td>Supports</td>
<td>Challenges</td>
<td>Other Comments</td>
</tr>
<tr>
<td>----------</td>
<td>------------</td>
<td>---------------</td>
</tr>
</tbody>
</table>
| • Break for parents | Food issues (for 1½ years) | Entry to preschool:  
| | • Refused to eat baby food when they started introducing solid foods | • Evident that M. was developmentally behind his classmates.  
| | • Did not gain weight between 1 and 2 years old. | Surprise at diagnosis  
| | • In hindsight, these were likely related to sensory issues | • Husband has family members with ASD but mostly higher functioning. So she was attuned to look out for signs. But M. appeared to be developing normally. |
| Prior to diagnosis | **“Easy child”**  
| | • He didn’t have very challenging behaviors, compliant  
| | • Development appeared to be typical | **Speed of Evaluation**  
| | | • Evaluation was quick.  
| | | **Informational support/ Developmental pediatrician**  
| | | • Provided list of resources.  
| | | • Provided guidance on what they needed to do next.  
| | | **Speed of receiving services**  
| | | • Quick. Diagnosis in March, Services in August.  
| | | **TEACCH**  
| | | • Answered questions (informational support)  
| | | • Parent education classes  
| | | **Friendships**  
| | | • From TEACCH parent classes who were in similar situations.  
| | | • “Extreme Parenting Group” who meet regularly, who understand, and help each other with questions.  
| | | **Church**  
| | | | **Food issues** were more of a stressor than the developmental concerns  
| | | **Concerns from people**  
| | | • People started to ask them to have him evaluated  
| | | • She looked up signs of autism and recognized some in him. (e.g., stimming, hand flapping, organizing toys)  
| | | **The diagnosis itself**  
| | | **Pressure to get services as soon as possible**  
| | | • High stakes  
| | | **Mourning period**  
<p>| | | • Adjusting expectations |</p>
<table>
<thead>
<tr>
<th>Supports</th>
<th>Challenges</th>
<th>Other Comments</th>
</tr>
</thead>
</table>
| • Special Ed. Teacher who takes care of on M. till now, which allows respite for parents  
• Provides a community of people that care about him. | **Challenging behavior issues**  
• Biting, pinching, pulling hair, tantruming  
• Not sleeping (walking up several times at night  
• Fecal smearing  
• Elopement |  |
| 6 month after diagnosis (almost at age 4) | **Scheduling Services**  
• Getting the services, coordinating scheduling  
• Time limitations of parents, both working |  |
| **TEACCH program**  
• Pre-K classes, OT, Speech | **Cost of services**  
• Expensive  
• Insurance coverage is limited for Speech and OT, unlimited psych, but no behavioral therapy  
• Additional appointments are out-of-pocket |  |
| **Younger Sister**  
• Her younger sister stayed with them for a year and brought him to his appointments | **Balance between work and managing schedules**  
• Need to work to pay for appointments, but difficult to take time off to get M. to appointments. |  |
| Present time (in pre-K) | **For M. ABA Therapy**  
• Observable changes in behavior – more | **Cost of services (ABA)**  
• Not covered by insurance and costs more than husband’s med school | **Transition meeting in April**  
• Will likely be in  |
<table>
<thead>
<tr>
<th>Supports</th>
<th>Challenges</th>
<th>Other Comments</th>
</tr>
</thead>
<tbody>
<tr>
<td>social, wants to interact with people and his family</td>
<td>Lack of coordination among service providers</td>
<td>autism classroom, with pull-out for certain activities where he can be mainstreamed (e.g., PE, Lunch)</td>
</tr>
<tr>
<td>• Challenging behaviors have resolved – sleeping, elopement</td>
<td>• Different providers have different approaches</td>
<td></td>
</tr>
<tr>
<td><strong>Other activities</strong></td>
<td><strong>Attitude of service providers</strong></td>
<td></td>
</tr>
<tr>
<td>• Swimming after school – provides sensory input</td>
<td>• Speech therapist lack of understanding of M.’s behaviors</td>
<td></td>
</tr>
<tr>
<td><strong>Good relations with teachers and teacher aides.</strong></td>
<td><strong>Implementation of multiple approaches</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Good teacher-student ratio</strong></td>
<td><strong>School/Conflict in availability and suitability of options</strong></td>
<td></td>
</tr>
<tr>
<td><strong>For Parents</strong></td>
<td><strong>Lack of parent-teacher communication</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Family financial support</strong></td>
<td><strong>Limitations of current classroom</strong></td>
<td></td>
</tr>
<tr>
<td>• Family member pays for ABA therapy</td>
<td>• No verbal children in class, no one to practice verbal and social skills with</td>
<td></td>
</tr>
<tr>
<td><strong>Friends</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Assist in getting M. to appointments</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Work environment</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Flexibility at work place allows her to leave work early to pick M.</td>
<td></td>
<td></td>
</tr>
<tr>
<td><strong>Availability of resources in this area</strong></td>
<td></td>
<td></td>
</tr>
<tr>
<td>• Examples?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

**What Can Be Improved?**

- Autism Parity Bill that mandates insurance coverage for autism
- School system providing opportunities for children with autism to have more interaction with typically developing children.
- In future, having support groups for the child with autism as he grows older, to interact with other people with autism.
- Government to invest more in early childhood intervention to improve their skills and increase opportunities for greater independence as opposed later on when, as adults, these individuals may need to live in group homes or be on social security disability

**Suggestions for other parents:**

- Connect with people who are in the same situation
- Realize that the mourning period lessens with time
## APPENDIX H: THEMES AND SUB-CODES

### Codes for Stressors

<table>
<thead>
<tr>
<th>Stress - Child</th>
<th>Stress - Macro - State-level Systemic Issues</th>
</tr>
</thead>
<tbody>
<tr>
<td>• academics</td>
<td>• balancing work-family</td>
</tr>
<tr>
<td>• age-ing out services</td>
<td>• denial</td>
</tr>
<tr>
<td>• behavior challenging, autism symptoms</td>
<td>• emotional state, depressed, tired</td>
</tr>
<tr>
<td>• development - prior diagnosis</td>
<td>• external factors, work</td>
</tr>
<tr>
<td>• development - uncertainty, fluctuation</td>
<td>• having more children in future</td>
</tr>
<tr>
<td>• developmental lag</td>
<td>• health, older age</td>
</tr>
<tr>
<td>• diagnosis unexpected OR regression OR changes in beh</td>
<td>• lack of awareness, missing the boat</td>
</tr>
<tr>
<td>• external - moving, change environment</td>
<td>• lack of time, need for downtime</td>
</tr>
<tr>
<td>• general caring</td>
<td>• marital issues</td>
</tr>
<tr>
<td>• growing up, desire for independence</td>
<td>• reaction to diagnosis</td>
</tr>
<tr>
<td>• increased size, age, smarts, arms race</td>
<td>• sense of doing this on your own</td>
</tr>
<tr>
<td>• limited skills, social, financial</td>
<td>• single-parent</td>
</tr>
<tr>
<td>• medical, comorbid disorders, health</td>
<td>• suspicions</td>
</tr>
<tr>
<td>• need to be taught everything, constant vigilance, need for constant attn</td>
<td></td>
</tr>
<tr>
<td>• safety, elopement</td>
<td></td>
</tr>
<tr>
<td>• skills-work fit difficulties</td>
<td></td>
</tr>
<tr>
<td>• worry - future, planning transition</td>
<td></td>
</tr>
<tr>
<td>• worry for child</td>
<td></td>
</tr>
<tr>
<td>• everything depends on child's beh</td>
<td></td>
</tr>
<tr>
<td>• pressure, high stakes involved</td>
<td></td>
</tr>
<tr>
<td></td>
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<tr>
<td>Stress - Extended Family</td>
<td></td>
</tr>
<tr>
<td>• lack of support</td>
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<tr>
<td>• lack of understanding</td>
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<tr>
<td>Stress - Family Nuclear</td>
<td></td>
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<tr>
<td>• general, care for other chn (non-asd)</td>
<td></td>
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<tr>
<td>• lack of family time</td>
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<tr>
<td>• multiple children w disability</td>
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<tr>
<td>• spouse</td>
<td></td>
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<tr>
<td>• sacrifices, tradeoffs</td>
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<tr>
<td>Stress - Finance</td>
<td></td>
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<tr>
<td>• general</td>
<td></td>
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<td>• high cost of services</td>
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<td>• ineligibility for aid</td>
<td></td>
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<td>• insurance limited coverage</td>
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<td>• long waitlist for aid</td>
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<tr>
<td>Stress - Friends - Lack of Support, Loss of Friendships</td>
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<td>Stress - Govt - General, Unhelpful</td>
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<td>Stress - Social - Isolation</td>
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<tr>
<td>Stress - Societal - Lack of Understanding</td>
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</tbody>
</table>
Codes for Supports & Resilience

support - formal - financial (e.g., Medicaid, state/federal-waivers, etc)

support - formal - school
- courses
- general
- parent-tr communication
- structure
- teachers, service provider, staff

support - formal - service, service provider
- service providers
- services - efficacy, improved beh, skills
- services - general
- services - information, parent education
- services - network w other parents
- services - quick evaluation
- services - receiving diagnosis
- services - respite, providing additional pair of hands
- services - suggestions for parents

support - informal - child
- general progress
- progress- lesser challenging behavior
- skills, ability
- child char - easy to care for, personality etc

support - informal - church

support - informal - extended family
- attitude
- childcare
- financial
- general

support - informal - family nuclear
- child's sibling
- general
- spouse - general
- spouse - strong marriage

support - informal - friend
- friend - emotional, info
- friend - practical help
- friend - provide peer companion for child
- other parents of chn w disab, ASD
- other people, professionals(who were not acting in the capacity of professionals)

support - location - resource-rich

support - other - for parent
- self - having time to research
- self - lack of awareness
- vices
- other - counselors for parents, events, meds, work as respite
- other resources

support - other - parent work - understanding environment, self-employed

support - resilience - child strength - resilience, perseverance

support - resilience - family strengths - adjust, adapt, accommodate

support - resilience - parent strength
- accepting child, realistic, understanding
- advocacy, fight, raising awareness
- appreciate, being thankful
- communication w siblings
- do the best, all you can, what u can, figure it out
- early planning
- getting help for self
- humor, have fun, optimistic, different rather bad
- love, pride
- other, general
- parenting skills
- perseverance, hope, determination
- prior knowledge, experience, vigilance
- proactive, initiative, resourceful, research
- self-education
- self-efficacy
- wait and see, a step at a time
General Codes:
Advice | Expectations/goals/dreams/hopes | Potential supports/improvements

advice for other parents
- be open about diagnosis, explain
- consider medical options
- do what you need for yourself
- fight, get to work, don't give up
- find your child
- general
- it's not a death sentence, just different
- life's little lessons should not be lost just because your child is disabled
- praise, encourage child
- seek connections, info
- things get better

expectation, goals, dreams, hopes
- changing
- initial, at diagnosis
- initial, prior diagnosis
- present, future
- uncertainty of child's progress and potential

potential supports, improvements
- early intervention, identification
- education
- finance, insurance
- improved system, coordination
- more support general
- specially trained professionals
- support for adults
- support for other chn w disab

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## APPENDIX I: SAMPLE THEME, SUBCODE, AND EXAMPLE/QUOTE/SUMMARY

<table>
<thead>
<tr>
<th>Code</th>
<th>Subcode</th>
<th>Example/Quote/Summary</th>
<th>Stage</th>
<th>Parent</th>
</tr>
</thead>
<tbody>
<tr>
<td>Stressors</td>
<td>child-related</td>
<td>challenging behavior issues, e.g., irregular sleep, tantrum, smearing faeces, hitting, biting</td>
<td>prior; current</td>
<td>E1/E2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>health issues/comorbid disorders/illness: not eating, not gaining weight between 1-2y/o; CFD, mitochondrial disease, generalized anxiety disorder, limited food intake-feeding tube</td>
<td>prior; prior; current</td>
<td>E1/E2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>prior to diagnosis: fairly typical development-unexpected diagnosis (e.g., speaking at 10 months, joint attention, sociable). Physical development was typical (e.g., crawling, walking) except for speech and awareness</td>
<td>Prior</td>
<td>E1/E2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>worry about future: bullying in future school, lack of independence, uncertain about her possible progress because of the inconsistencies in her skills.</td>
<td>current-future</td>
<td>E1/E2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>seeing his developmental lag when compared to other children</td>
<td>Prior</td>
<td>E1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>safety, elopment issues</td>
<td>prior; current</td>
<td>E1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>limited skills (global developmental delays), limited verbal skills, limited daily functional skills</td>
<td>prior; current</td>
<td>E2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>constant vigilance/attention required for child</td>
<td>current</td>
<td>E2</td>
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<td></td>
<td></td>
<td>fluctuation in development</td>
<td>current</td>
<td>E2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>general caring for child</td>
<td>current</td>
<td>E2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>increased size, age: hitting has more impact than before</td>
<td>current</td>
<td>E2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>need to be taught everything</td>
<td>general</td>
<td>E2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>worry about child: vulnerability of child, how others will treat her.</td>
<td>current-future</td>
<td>E2</td>
</tr>
<tr>
<td>Family</td>
<td></td>
<td>having multiple children with disabilities</td>
<td>general</td>
<td>E2</td>
</tr>
<tr>
<td>Finance</td>
<td></td>
<td>limited insurance coverage</td>
<td>general</td>
<td>E1/E2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>high cost of services</td>
<td>general</td>
<td>E1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>general finances are tight, esp with single parent/income household</td>
<td>general</td>
<td>E2</td>
</tr>
<tr>
<td>Parent</td>
<td></td>
<td>Reaction to diagnosis: mourning; crushed, depressed</td>
<td>initial</td>
<td>E1/E2</td>
</tr>
<tr>
<td>Code</td>
<td>Subcode</td>
<td>Example/Quote/Summary</td>
<td>Stage</td>
<td>Parent</td>
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<td></td>
<td></td>
<td>worry about having more children</td>
<td>current</td>
<td>E1</td>
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<tr>
<td></td>
<td></td>
<td>lack of autism awareness</td>
<td>Prior</td>
<td>E1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>pressue to get services, therapy due to high stakes, importance of EI</td>
<td>initial</td>
<td>E1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Denial prior to diagnosis</td>
<td>Prior</td>
<td>E2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>emotional state - anxiety, anger, depression, fear</td>
<td>initial</td>
<td>E2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>parent health: disabled veteran; accident prior to interview</td>
<td>prior; current</td>
<td>E2</td>
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<tr>
<td></td>
<td></td>
<td>lack of time?</td>
<td>general</td>
<td>E2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>marital issues: left husband</td>
<td>Prior</td>
<td>E2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>being new to the system</td>
<td>initial</td>
<td>E2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>single-parent stressors</td>
<td>general</td>
<td>E2</td>
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<tr>
<td>School</td>
<td></td>
<td>poor quality of public schools especially for special ed.</td>
<td>general</td>
<td>E1/E2</td>
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<tr>
<td></td>
<td></td>
<td>lack of teacher-parent communication</td>
<td>initial</td>
<td>E1</td>
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<tr>
<td></td>
<td></td>
<td>lack of suitable options for child to interact with TYP children</td>
<td>initial; current</td>
<td>E1</td>
</tr>
<tr>
<td>services/</td>
<td></td>
<td>therapist attitude: lack of understanding</td>
<td>initial</td>
<td>E1</td>
</tr>
<tr>
<td>service providers</td>
<td></td>
<td>assessing supports: difficulty</td>
<td>initial</td>
<td>E1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>coordinating services/lack of cohesion among services</td>
<td>initial</td>
<td>E1</td>
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<tr>
<td></td>
<td></td>
<td>implementing therapies at home</td>
<td>initial</td>
<td>E1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>scheduling, logistics: arranging family's schedules to get child to therapies</td>
<td>initial</td>
<td>E1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>insufficient availability, availability inconsistent</td>
<td>current</td>
<td>E2</td>
</tr>
<tr>
<td>Sacrifices</td>
<td></td>
<td>competitive work; social life: giving up what you want for what is needed</td>
<td>current</td>
<td>E1/E2</td>
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<tr>
<td></td>
<td>balancing work-family life</td>
<td>both parents need to work to pay for appointments, but they need time off from work to get him to appointments</td>
<td>initial; current</td>
<td>E1</td>
</tr>
<tr>
<td>Social</td>
<td></td>
<td>Isolation</td>
<td>initial</td>
<td>E1/E2</td>
</tr>
<tr>
<td>Supports</td>
<td>child-related</td>
<td>progress in skills and behaviors</td>
<td>current</td>
<td>E1/E2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>lesser challenging behaviors</td>
<td>current</td>
<td>E1</td>
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<tr>
<td></td>
<td></td>
<td>child character - easy to care for</td>
<td>general</td>
<td>E1</td>
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<tr>
<td></td>
<td></td>
<td>service providers attitudes and helpfulness</td>
<td>current</td>
<td>E1/E2</td>
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<td>Stage</td>
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<td></td>
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<td>services: (for child) efficacy, positive child behavioral outcomes</td>
<td>current</td>
<td>E1/E2</td>
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<tr>
<td></td>
<td></td>
<td>services: (for parents) general support, usefulness for parents, information, providing network with other parents, quick evaluation; respite</td>
<td>initial; current</td>
<td>E1/E2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>Financial</td>
<td>initial; current</td>
<td>E2</td>
</tr>
<tr>
<td>Informal</td>
<td></td>
<td>family: child's sibling</td>
<td>initial; current</td>
<td>E1/E2</td>
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<tr>
<td></td>
<td></td>
<td>family: spouse (involved with the children), having a strong marriage</td>
<td>general</td>
<td>E1</td>
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<tr>
<td></td>
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<td>extended family: emotional support, practical (childcare), financial (paying for therapy)</td>
<td>initial; current</td>
<td>E1</td>
</tr>
<tr>
<td></td>
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<td>friends: practical (ferrying child to appointments, babysitting), kids of same age</td>
<td>current</td>
<td>E1/E2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>friends of children with disabilities/ASD: understanding, helping with questions</td>
<td>current</td>
<td>E1/E2</td>
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<tr>
<td></td>
<td></td>
<td>community that cares e.g., church</td>
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<td>E1</td>
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<tr>
<td>external</td>
<td></td>
<td>location: staying in a resource-rich location</td>
<td>current</td>
<td>E1/E2</td>
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<td></td>
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<td>parent's work place - flexible hours</td>
<td>current</td>
<td>E1</td>
</tr>
<tr>
<td>Resilience</td>
<td>parent</td>
<td>accepting diagnosis; being realistic about child's capabilities</td>
<td>initial; current</td>
<td>E1/E2</td>
</tr>
<tr>
<td></td>
<td>strengths</td>
<td>humor, having fun, optimistic</td>
<td>general</td>
<td>E1/E2</td>
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<tr>
<td></td>
<td></td>
<td>doing the best you can, doing all you can</td>
<td>general</td>
<td>E1/E2</td>
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<tr>
<td></td>
<td></td>
<td>prior knowledge/background: pre-med background &amp; experience with older son's diagnosis; family history of autism</td>
<td>Prior</td>
<td>E1/E2</td>
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<tr>
<td></td>
<td></td>
<td>appreciative, being thankful</td>
<td>current</td>
<td>E1/E2</td>
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<td>vigilance: &quot;I always try to be really attuned to looking for like developmental issues with them&quot;</td>
<td>Prior</td>
<td>E1</td>
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<tr>
<td></td>
<td></td>
<td>love, pride</td>
<td>general</td>
<td>E1</td>
</tr>
<tr>
<td></td>
<td></td>
<td>perseverance, determination, hope</td>
<td>initial; current</td>
<td>E2</td>
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<td></td>
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<td>fight, advocacy, raising awareness</td>
<td>initial; current</td>
<td>E2</td>
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<td>Code</td>
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<td>proactive, initiative, resourceful</td>
<td>prior; initial; current</td>
<td>E2</td>
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<td></td>
<td></td>
<td>self-education</td>
<td>initial; current</td>
<td>E2</td>
</tr>
<tr>
<td></td>
<td></td>
<td>self-efficacy</td>
<td>current</td>
<td>E2</td>
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<tr>
<td></td>
<td>family strengths</td>
<td>adjusting, adapting, accommodating</td>
<td>general</td>
<td>E1/E2</td>
</tr>
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</table>
REFERENCES


